



(Re)arranging “systems of care” in the early Ebola response in Sierra Leone: An interdisciplinary analysis

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ABSTRACT

Despite an expanding literature on Ebola-response, few studies detail or reflect on the responses of diverse systems of care. Little is known about how, why or in what ways, strategies of ill-health management were enacted locally, how health-systems power, authority and hierarchy were perceived and contested, or how other social systems, institutions and relationships shaped the response.

This paper presents an interdisciplinary analysis of local responses in two early affected districts in Sierra Leone. Drawing on anthropological theories of social ordering and assemblage, we present an analysis of contrasting infection chains in three extended case studies from Bo and Moyamba districts. In contrast to previous scholarship which has understood local actions as being reactive (supporting or obstructing) to a national Ebola response, we show that local arrangements lead and shape responses. Our cases show how multiple, entangled, dynamic and co-existing systems of care influence these responses. Some individuals and communities collaborated with health authorities on measures like reporting and quarantine, others actively opposed them, or played an intermediary role. Collectively, formal health systems actors, local authorities and ordinary citizens negotiated and enacted new arrangements. These arrangements involved compromise and sometimes power was reconfigured. They were also shaped by wider political and historical contexts and by availability or absence of formal healthcare resources. Our research shows the critical importance of understanding how institutions and people involved in healthcare enact diverse “systems of care” and thereby shape Ebola response. Most importantly, our work underlines the need for alignment between formal health-systems and wider social, cultural, political and economic forms of organisation at family and community levels to improve crisis-response and promote sustainable care. In particular, health systems responders need to identify and engage with key brokers – or arrangers – in frontline care systems, with whom mutually acceptable, and effective, reconfigurations of care can be achieved.

1. Introduction: Conceptualising “Systems of care” in Ebola response

When Ebola broke out in Sierra Leone in 2014–15 it was an entirely new disease for the West Africa region. Early response was driven by health security concerns and led by heavily militarised actions that failed to grasp local contexts of healthcare – an approach that has been heavily criticised (e.g. De Waal, 2014; Gulland, 2015; Wilkin and

Conteh, 2018; Horton, 2019). One question receiving less attention is whether and how a better understanding of and engagement with local health systems might have helped improve response. The health system is typically taken to mean the formal “system” of care, though exact configurations vary. Health systems strengthening is a key objective of governments and donors, particularly where severe shocks are created by disease outbreaks, natural disasters, and political and economic crises (Hanefeld et al., 2018). A highly-functioning health system is perceived

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to be resilient to these kinds of shocks, in the sense of being able to continue to safeguard a basic level of care in a crisis. Resilience is increasingly seen by international institutions as an aspirational goal (WHO, 2014). However, the concept of resilience —“*the capacity of individuals, families, communities, systems and institutions to anticipate, withstand and/or judiciously engage with catastrophic events and/or experiences...*” (Blanchet et al., 2017:p.308)—does not pertain just to the health system but involves capacities of a broader range of stakeholders. This implies that resilient healthcare systems are networks of “systems” operating at multiple levels, from institutions to individuals. Yet, health sector responses often treat the system as monolithic without recognising nuances or incentives operating at different levels.

The Ebola response in Sierra Leone, to be described in this paper, revealed unpredicted conflicts and challenges when health, military and humanitarian systems (national and international) collided with local health systems (themselves already a hybrid between local and science-based knowledge and practice) and families and communities. International Ebola-response experts were mainly familiar with localised outbreaks in other parts of Africa. They had never before had to deal with a full-blown epidemic with rural and urban dimensions, and thus their explanatory schemes and operational protocols had to be adjusted to a new set of social realities while at the same time embracing a high level of existing health-systems hybridity (Walsh and Johnson, 2018). The tensions between international responders and local systems of belief and practice have been well documented in anthropological scholarship (Fairhead, 2016; Richards, 2016; Lipton, 2017; McKay and Parker, 2018). Anthropological literature was also hugely important in highlighting how local care shaped the Ebola response in Sierra Leone and elsewhere (Abramowitz, 2017; Chandler et al., 2015; Ebola Anthropology Response Platform, 2016). However, much of this literature does not engage directly with health systems literature on structures and processes, nor does it analyse health systems perspectives or the implications of tensions for health systems responses. Our paper attempts to bridge this gap by considering how diverse systems and arrangements of care responded during the chaos of early Ebola response.

“Messy” complexity is not at all uncommon in the sphere of global disaster management and requires social scientists to reconsider how their theoretical schemes work (Law, 2004). Law’s challenge to meet mess head-on aims, in fact, not to straighten out the mess with more rigorously applied theory, but to adjust our theoretical sights to help in the task of living with the reality of mess. To this end, we have drawn inspiration from both Post-Structuralist (Deleuze and Guattari, 1987; Buchanan, 2020) and neo-Durkheimian explanatory traditions (Collins 2004, 2008, 2008; Douglas, 2007; Smith, 2020).

Deleuzian post-structuralism provides us with the helpful notion of “agencement”, sometimes translated as “assemblage” but perhaps better understood as “arrangement”, as in arrangement of a piece of music for the forces at hand (Buchanan, 2020). The term serves to characterise, in abstract terms, the capacity to combine essential elements of a system in unprecedented, improvisatory ways to achieve effective levels of performance.

Neo-Durkheimian theory (Smith, 2020), as distinct from theory propounded by Durkheim himself, focuses on mechanisms and processes of change in organizational values, and is useful in helping us understand what it is that actors have to enact, and how they use ritual to tackle open-ended and at times unprecedented collaborative tasks. Collins (2004: 372), for example, traces out complex processes of social engagement unfolding across chains of ritual interaction, thereby focusing attention on a “radical microsociology” of causal mechanisms. For similar reasons, Mary Douglas examines poetic and ritual composition as a performative resource for reducing the clash of rival systems of moral ordering, when refocusing social creativity “after a revolution or a long war” (Douglas, 2007: 148, see also 6 & Richards, 2017).

With such theoretical resources in mind, we examine ways in which, in the heat of Ebola engagement, healthcare systems were reconfigured to achieve coordination and cooperation among and between hastily

and expensively assembled and at times mutually incompatible health system elements, resulting in eventual effective Ebola control. Through situated analysis of responses to local infection chains, we discover coherence in processes that at first seem largely chaotic. In particular, we focus on contributions made by grass-roots actors and structures to this open-ended process of crisis management. We focus on small town and semi-rural settings, which have received less attention in existing literature. These areas have connections both to the rural locales surrounding them and to bigger towns or cities, and typically reflect hybrid healthcare through formal health facilities and/or community-based health workers as well as traditional forms of healing. Our focus on one small town and two semi-rural locations enables a new vantage point for exploring interactions between different kinds of authorities, at the interface between formal health systems and other kinds of health care during Sierra Leone’s Ebola epidemic.

2. Methods

Data were collected by the Ebola Gbalo (“Ebola Trouble”) research group between 2016 and 2018. Our interdisciplinary study analysed different levels of the Ebola response (community, district, national and international) in Sierra Leone and the nature of interactions between the different actors and elements of the response (Ebola Gbalo, 2019). Our methodology drew on the range of specialisations that team members brought: health systems research, anthropology (social, medical and ecological) and clinical health research and practice. We combined ethnographically-informed with health systems research approaches. In addition we traced infection chains through qualitative reports of sickness confirmed by epidemiological reports and clinic records. This enabled us to reveal the carers and responsible authorities responding to infections and thus to understand the “systems” in operation. We present three extended case studies examining the role of powerful actors in formal and informal systems of care, the ways in which they responded to infections, and the conflicts and compromises that enabled new configurations of care to emerge.

The study focused on two early affected, adjacent districts in Southern Sierra Leone: Bo and Moyamba districts. For this paper we selected two villages (Villages A and B) in Bo and one small town (Town C) in Moyamba which are under-represented in existing Ebola response literature. Further selection criteria were: outbreaks that illustrate changing response configurations over time; outbreaks that were relatively quickly contained, providing important information about “what went right”; and availability of good qualitative and epidemiological (infection-chain) data for the chosen sites.

The ethnographic mapping of infection chains involved first identifying chiefdoms and villages that had contrasting outbreaks at different points in the epidemic (large, small, quickly contained, longer-lasting outbreaks). For each we then identified probable index cases and traced, from a wide range of respondents, how the infection spread. Where possible, information on infections was then cross-checked with epidemiological records (see below). This method (described in more detail in Richards et al., 2020) helped to identify respondents for key informant interviews. In total, 96 in-depth, narrative-style, interviews were carried out with respondents across the two districts. These included managers in Peripheral Health Units (PHUs) and District Health Management Teams (DHMTs) involved in decision-making during the Ebola epidemic. Local Government/non-health authorities were purposively selected for their involvement in decentralised health services at the district level. These included district chairpersons, key local authorities (at various levels) and representatives of local NGOs and community groups. Additionally, group interviews elicited shared community perspectives on the actions and performance of various actors during the epidemic. Before conducting the interviews, local authorities were notified once villages of interest were identified through the infection-chain mapping. Community-level informed consent was obtained in meetings held to explain the project, attended by local chiefs

and elders. Interviewees were given detailed information sheets and asked for consent. Most interviews were recorded using recording devices or notes written-up as soon as possible after the interview.

We triangulated our qualitative infection chain data with epidemiological records held for the study districts. The primary source of “official” data was admission data collected on (WHO-standard) Ebola Case Investigation Forms, completed when a person suspected of having Ebola presented to a care or holding facility. The reliability of this information is questionable due to pressures on medical staff during admission of a suspected Ebola case (Richards et al., 2020), but in many cases it is all we have. Where possible we sought facility-level laboratory records of tests for Ebola applied to blood or swab samples. In particular, we were given (by the compiler) a hand-written log of admissions, test results and outcomes from the Ebola Holding Centre in Moyamba District, operating from June to November 2014. This was important for confirming statements made by eyewitnesses of the early stages of the epidemic but not covered in the national Ebola data base.

Analysis of all data, for the wider Ebola Gbalo study and for this paper, was conducted jointly, drawing on the contextual knowledge of our Sierra Leonean researchers (and co-authors) who had themselves been embedded in their district response efforts. This important “insider” knowledge, tempered with the “outsider” knowledge of the UK researchers, enabled a richer, and more nuanced interpretation of the data. Nvivo was used to help manage coding for the wider project, but for this paper the infection-chain and response narratives were analysed manually. The lead author (SM) developed a chart mapping data on different systems of response, which was used by the co-authors for data analysis.

2.1. Study limitations

We began collecting data a year after the Ebola epidemic ended, so our data rely on the accuracy of informants’ recollections. To minimise recall and courtesy biases we triangulated accounts of health care workers and communities across multiple interviews, following up inconsistencies. Most people invited to be interviewed accepted and there was willingness to talk openly. Some community respondents preferred to speak in private, while others preferred a group setting.

3. Findings: Negotiating care practices and systems during crisis

3.1. Infection chain trajectories

Table 1 shows deaths from Ebola across the two districts in relation to the chiefdoms and towns being studied. Ebola probably first reached Sierra Leone across the Guinea border in March 2014, though the

outbreak was not officially declared until May 21st. The first cases were in the Eastern Province but spread to the Southern Province within a matter of weeks. Deaths (and population numbers) across Bo and Moyamba Districts, and case-study chiefdoms and settlements, are shown in Table 1. Bo District, with its larger population, key road junctions and high levels of trade in the district headquarters, saw more cases. Outbreaks in Villages A and B occurred at the beginning and towards the end of Bo district’s epidemic. The outbreak in Town C occurred in the middle of Moyamba District’s epidemic.

The next three sections present narratives of the complex unfolding of relations between different authorities and kinds of carer and how these shaped burial and care practices. Through these narratives we show that any understanding of a healthcare ‘system’ has to embrace these layers of relationships and the way that tensions between them are (or are not) resolved.

3.2. Village A, Bo District

3.2.1. Trusted and socially connected leadership maintained order and cooperation in the face of tragedy, and inspired rearrangements of village burials, halting infection spread

This settlement (about 15 km from Bo city on a good road) was the site of Bo District’s first large outbreak, starting in early June 2014. This was almost two months before the government declared a national emergency on 30th July and WHO’s announcement that Ebola in West Africa constituted a Public Health Emergency of International Concern on 11th August. This announcement triggered international assistance.

Village A was the home of a respected *kaamoh* (Arabic teacher) who became infected while attending a funeral of an Ebola victim in another village. When the *kaamoh* died, in Village A, he received a Muslim burial involving washing the body. This was authorised by the Paramount Chief (to whom the family was connected) since no Ebola was yet suspected. Soon afterwards, the *kaamoh*’s pregnant wife (daughter of Village A’s chief) felt unwell and sought treatment at a Health Centre (HC1) in a neighbouring settlement.

Meanwhile, Bo District Health Management Team (DHMT) had kept its health workers on high alert after receiving, and acting on, information from colleagues in Kenema, where early cases were being treated. Hence, staff in all health facilities were well informed about Ebola signs and possible symptoms and how to protect themselves with the limited resources they had, as the health worker at HC1 who treated the *kaamoh*’s wife informed us:

“First of all, they supplied us gloves. Enough gloves and they told us that we should be using gloves and that we should double the gloves. We were doubling the gloves. Then we were also given chlorine which we used to

Table 1

Ebola deaths, Bo and Moyamba districts and case-study Towns.

Location	June 2014	July 2014	Aug 2014	Sept 2014	Oct 2014	Nov 2014	Dec 2014	Jan 2015	Feb 2015	TOTAL deaths
Bo District	1	15	33	35	80	96	48	7	0	315
572,000 population										
Kakua Chiefdom	1	9	23	20	36	38	23	2	0	152
51,000 population										
Case A	X	X	X							37
691 people										
Bumpeh Ngao CD	0	0	0	0	7	19	18	4	0	48
44,000 population										
Case B 702 people						X	X	X		5
Moyamba District	0	2	8	42	44	67	26	15	6	211
318,000 population										
Lower Banta CD	0	0	0	2	4	24	6	0	0	36
37,000 pop.										
Case C, 2000 people.					2	22	6			30

Population data from National Population Census (2015). X = cases, but exact numbers unknown.

Source: Case data of confirmed Ebola + deaths from Bo and Moyamba Districts from the consolidated national dataset, a copy of which is held at the Njala Ebola Museum and is used here with permission.

mix 0.5 to wash our hands at first. [...] That was what saved us. [...]"
Health worker, HC1.

When the *kaamoh's* wife arrived, she showed no Ebola symptoms (being in the "dry" phase). Nevertheless, the nurse in the health centre wore two pairs of gloves as she had been instructed then changed gloves and cleaned properly between patients. This effectively prevented onward infection at the health facility. The nurse was told that the woman's husband had died and questioned where he was from – she was told from Village A (where there were no known infections), but no mention was made of the village where he had attended the funeral and where there were known infections. *"If they had told us, we should have isolated them here and called the office to come to their aid [as possible Ebola cases] [...]. But they did not explain."* MCH Aide, HC1.

The wife returned home where she later delivered the baby, but both died. The nurse followed up for routine reporting on maternal health outcomes, and on hearing about the deaths she alerted the DHMT. They treated the deaths (routinely) as possible Ebola infections and sent in the District Surveillance Officers (DSOs) to investigate. When positive cases were confirmed the health centre was quarantined.

Meanwhile the Village A's chief had also gone to the paramount chief in Bo city with his concerns about illness in his village and from there to the district authorities, who told him no one must touch anyone else until the cases were confirmed or not. The *kaamoh's* brother then fell sick and died. This time his body was not buried by the townspeople; they waited (three days) for the newly-established district burial team. When the body was confirmed Ebola positive, the District Medical Officer, District Chairman and the heads of police and local military (who were all part of the locally established District Ebola Response Taskforce) arrived to speak with the town chief.

The village people, however, were initially reluctant to engage with the DSO investigation. Rumours circulated, mostly by word of mouth but also aired on radio phone-ins, suggesting that Ebola was political misinformation from the government (Bo was an opposition district at the time) trying to undermine opposition strongholds, or that it was an internationally-manipulated crisis intended to generate sale of blood and body parts. There was also uncertainty about what a diagnosis meant – it was known from people who travelled from Kenema that suspected cases were isolated and houses quarantined, and that there were high death rates, so there was fear as well as suspicion. But no one admitted to having contact with known or suspected Ebola cases, and health workers were seen as informers bringing unnecessary hardship.

At the leadership level, there were historically good relations between the chieftaincies and Bo District authorities (who had collaborated in the face of rebel attacks during the civil war, 1991–2002). Village A's chief was committed to cooperating with district authorities in the face of the latest crisis. Furthermore, the town chief and his paramount chief were on good terms with each other and with the district authorities; they both trusted and reinforced the health-response messages coming from the district and supported the chieftom bye-laws first developed in the affected Eastern provinces. The Paramount Chief and village chief therefore met with the district hierarchies to discuss their response. With their agreement, a Bo district Ebola Taskforce quarantined Village A and removed the sick, who now numbered around 13. Because the chiefs were respected and trusted (with kinship and marriage links to the town), the townspeople cooperated and allowed sick family members to be taken to Bo government hospital. District resources provided food for quarantined houses (paid for from funds pre-emptively raised by the district).

From here events took a tragic turn. Despite being on high alert and having raised substantial resources locally, Bo District did not have enough money to create and fund a quarantine wing at the hospital or to train and equip staff safely to care for large numbers of Ebola patients. There was no national or international support or standard operating guidelines. Therefore, with nowhere to safely hold the sick, they were returned to the village from which they came, but now housed in a

dilapidated school building with an armed guard to quarantine them. In the absence of any guidelines on safe care, all families could do was to leave food and water at the schoolhouse door. No health workers were able safely to attend them either. All the sick in the schoolhouse died; three years later the anger and anguish were still palpable:

"... the medical people said there were no beds in the hospital [...] They took them there for two days [and] they were not given food. They brought them back to that old school building. [...] It was an open building and it was during the rains. They deployed soldiers around them. After the [civil] war we forgot about guns but if someone falls sick and is being surrounded by men with guns, why have you brought in those guns? That is sufficient to kill someone. So, in [Village A] even if Ebola killed people, it was discouragement that actually killed [them] because you don't treat illness with guns. Sickness is all about encouragement. Those snacks, [those] drops of water that you give the person [...] we prepared food and when we took it to the sick, we were told not to go near them. So, the food was placed in the porch. Who amongst them will be able to get up and eat that food? There was nobody." (Village Chief, 2017).

Yet despite this terrible human tragedy, and the high levels of grief and resentment that it caused, cooperation continued; all new cases were promptly reported and taken for treatment because *"If we continue to keep the sick in our houses, it will be disastrous. We realised it was death. [...] When we notice that somebody is seriously sick, we will make calls and they will come and pick them up."* (Village Chief). After 21 days the deaths stopped, but quarantine remained in place for 42 days in all. Out of a total of 44 cases only seven people survived. But within four weeks the outbreak had been brought under control and there were no further infections.

Furthermore, compromises were established that provided a model for much later in the epidemic when national and international actors finally started to learn from this and other local responses. Two district burial teams (still operating without national support) could not bury all corpses in a timely manner – one community as was left waiting for a week – and the chief in Village A established his own burial teams, accepted by the district authorities because he had strictly complied with reporting, quarantining and instructing his townspeople until then. The local burial teams left the actual corpse handling to the Bo district team with their more specialist equipment: *"So we set up three burial teams. [...] When there is death here, by the time the burial team comes from Bo, first thing in the morning they will dig the grave. When another dies, another group digs the grave and so they took turns. [...] It is our people who dig the grave and cover it. All that the team from Bo did was to wrap the dead in a white cotton [cloth], put it in the body bag and lower it."*

3.3. Village B, Bo District

3.3.1. Chieftom loyalties clash with health systems staff but negotiated compromise achieves conflict-resolution in identifying and caring for the sick

The outbreak in Village B (Bo District) began in November 2014. By this time, some national and international resources were moving down to district level, and many national standard operating procedures were in place.

The first two deaths in Village B were of older people who were being treated for other health conditions and later confirmed Ebola + after routine swabbing, though it is not clear where either acquired their infection. After these deaths District Surveillance Officers investigated and about 40 people were quarantined – their houses guarded by soldiers, as was still routine. Movement in or out of a quarantined house risked a Le. 250k (c. \$25) fine. This caused some resentment in the village, some people feeling accused of illegally entering quarantine houses and lying about it.

The nurse at the village B health post, who had been treating one of the deceased, then saw the Section Chief (SC) who came, at the end of November, complaining of headache and body pains (which she had

suffered from previously); she was examined, with the nurse observing stringent infection prevention and control (IPC) protocols, tested (negative) for malaria and was given medicine for her pains, and returned home, only to return later that day feeling much worse. At this point the nurse referred her to Hospital A (a well-respected, church-supported facility in a nearby town). The SC ignored the referral for several days until she became too sick to walk. The SC's symptoms remained unspecific, however, so the family maintained it was not Ebola although the chief's sister noted her red eyes – a tell-tale sign – as well as her obvious and unexplained sickness. Finally, the family hired a taxi to take the SC to Hospital A, where a rigorous triage system revealed she had attended a funeral in Tikonko, where an outbreak was unfolding. She was prevented from entering the hospital and referred to the Bandajuma Ebola Treatment Centre (ETC) outside Bo city run by *Médecins Sans Frontières*.

Sometime later a pregnant woman (AA) was brought to village B's health post, tested positive for malaria and was treated, but returned a few days later in premature labour. The baby was stillborn and AA started vomiting. The nurse became suspicious and threw chlorine over the vomit. When the mother reported her daughter was passing frequent stools the nurse, after consulting the mother, called the Community Health Officer (CHO) Chiefdom Supervisor at Hospital A. The Supervisor arranged to send an ambulance – the same one that had transferred the SC to Bandajuma ETC. Additionally, two village contact tracers identified that there were three sick children in a quarantine home connected to one of the first deaths. All were collected and taken to the ETC. The SC and AA both died shortly afterwards, and their households were quarantined. The three children survived. Contact tracing was stepped up, with support from the Paramount Chief, and more cases were reported and removed. Sixty more people were quarantined and a total of 13 cases confirmed. Eventually the whole settlement was quarantined for 21 days, after which cases ceased.

In the outbreak in Village B there were more survivors (8) than deaths (5), in contrast to the earlier tragedy of Village A. A number of factors contributed to this better outcome. The actions of the nurse and the robust triage and rapid response of staff at Hospital A ensured no further infection while rapid removal and extensive quarantine contained further spread. The better treatment possibilities available, notably in Bandajuma ETC, at this later stage in the epidemic also meant more people survived. Critically, a major funeral was averted because the Section Chief died at Bandajuma ETC, after being confirmed Ebola+, so no funeral was held.

Nevertheless, there were significant tensions after the chief's death; chiefdom loyalties and social systems of family-care and community support clashed with formal health systems requirements and a trusted broker was needed to resolve the conflict. Villagers resented the removal of their section chief and accused the nurse of over-stepping her authority to refer her. The CHO Chiefdom Supervisor put it in these terms: *“Unfortunately, community [B] went against the nurse for referring their Madam [chief] to hospital. [...] I went to community [B] myself in order to prevail on the leaders to retain the nurse but they were adamant that she should not work in their village any longer. The point they were making was that if [she] had not referred Madam to Hospital A she [would not have been] taken to the treatment centre [where she died].”*

The townspeople, deprived of their Chief, held a meeting which *“ended in chaos”* (community group interview) and eventually the Paramount chief had to intervene to calm the situation. Even he could not bring villagers to accept the continuing services of their nurse – the townspeople continued to boycott the health facility until district health authorities agreed to transfer the nurse elsewhere. The work of two community-embedded contact tracers was also rendered difficult by the tensions. Both faced significant pressures. Some community members accused them of collaborating with the District Ebola response, though others appreciated their efforts in helping to contain Ebola. With support from the paramount chief and the CHO Chiefdom Supervisor, and the compromise of transferring the nurse, continued health work was

mainly accepted by the community. Under new management, the clinic remains well used.

3.4. Town C, Moyamba District

3.4.1. Family loyalty, fear, distrust and inadequate health facilities hamper Ebola responses, requiring enforcement by local power brokers

There were two unrelated infection chains in Town C, both emanating from the bustling market town of Waterloo, near Freetown, where a large outbreak began in September 2014. Moyamba District was less cohesive than Bo, with open tensions between the (government-appointed) health sector authorities and the elected District Council Chair (representing a major opposition party). The authority of a number of chieftaincies in the District was also contested, linked to factionalism dating back to colonial times. Indeed, in Town C there were (and are still) tensions between the District's Paramount Chief and the Town Chief.

The first infection chain derived from two people who had travelled to Waterloo to attend the funeral of a relative later confirmed Ebola+. This triggered at least six cases and several deaths. Most of the sick sought advice from their resident CHO, who advised testing and referral, but none followed this advice and there were several breaches of the quarantine which had been imposed after the second death (the wife of a local contact tracer). Towards the end of this infection chain (in November) a 20-month old child died in a quarantined home. The Moyamba burial team arrived towards evening, almost too late for interment. There were people there who had not seen full PPE before and were afraid.

A combination of fear and misconception degenerated into physical assault of the burial team. After swab taking, the burial team had to abandon the burial and returned to Moyamba, leaving the corpse lying on the street, further diminishing public confidence in the burial process supervised by the DHMT. A local team was mustered to bury the corpse the next day. Unlike Bo District, there were no established local burial teams at this time. After this incident a local group, including sanitary officers and teachers approached the District chiefdom, religious and health authorities to discuss the need to support local burial responses. A local “auxiliary” team was then established but remained under-resourced until its supervisor mustered support from the international humanitarian agency World Vision who provided PPE and logistical support.

The second infection chain, from mid-November, was much more serious. When a 13-year old girl became sick in a household in Waterloo where seven people had already died of Ebola, her mother, in a desperate attempt to save her, persuaded the child's uncle to smuggle her to Town C, the mother's birthplace, for traditional healing. The uncle, who owned a commercial taxi operating between Waterloo and Town C, agreed.

The girl was hidden under goods, undiscovered by security personnel and Ebola Task Force Units at checkpoints and roadblocks between Waterloo Rural District and Town C. However, a relative visiting the house in Town C saw the sick girl and informed the police and chiefdom authorities, who investigated. The CHO was also consulted but seeing her condition he refused to treat. The girl died three days later and was buried with permission from the Town Chief but without permission of the Paramount Chief (PC) and in violation of established Chiefdom by-laws. The girl's uncle was fined for smuggling her and illegal burial. He paid both fines but the Town Chief refused to pay his own fine for authorizing burial, so he was suspended and replaced (to be reinstated only after the epidemic had ended).

Seven others in the household sickened in days following the girl's death and five died, including another child. The uncle's apprentice (FF) also later fell sick and sought help from the CHO, who suggested either a blood test or referral to the Ebola Holding Centre in Moyamba town. By now, fear of this notorious makeshift facility was widespread. Even late in the epidemic (November) the holding centre was woefully under-

equipped. Tests took several days to return during which time Ebola negative patients were at risk of cross-infection and only the most rudimentary palliative care was possible:

“the people that were handling those suspected cases were not trained even to give them water to drink [...] at that period, disaster [was] being caused all along, people were just dying, you understand?”. Replacement Town Chief, Town C.

Not surprisingly, FF rejected the CHO's suggestions, preferring to consult three different herbalists for treatment (two of whom later died of Ebola). FF died shortly afterwards. The bereaved family prepared the body for burial, then sought permission to bury the corpse, but the CHO and Chiefdom Speaker refused and called the Ebola hotline 117, insisting the corpse be handed over to the Chiefdom burial team. That resulted in further commotion, with the team attacked by villagers fearing quarantine and forced removals to the poorly-run holding centre.

This led to the local MP, CHO and (replacement) Town Chief jointly requesting military and police intervention. With a combined military and police presence, the Chiefdom Burial team arrived, conducted the burial and took a swab, returned positive three days later. This led to 50 contacts being traced and 10 homes being quarantined, this time with soldiers. Nineteen further cases occurred across several households, of whom only 6 survived. The replacement Town Chief told how they had to continue to remove the sick to the holding centre, despite its poor reputation, *“because that is the only alternative we had and we were able to contain the disease”* He noted that survival increased after better compliance with the authorities resulted in transfer to Bandajuma, with some cases going directly to a new ETC in Moyamba town opened by Norwegian volunteers in December 2014 (Haaskjold et al., 2016).

Militarised quarantine continued for several months. According to the replacement Town Chief, breaches stopped, but quarantine created significant hardship due to cessation of economic activity (including trading of foodstuffs). Unlike in Bo, there was no district resource to support food supplies. Eventually district authorities received help from the World Food Programme and various NGOs.

The refusal of the CHO in the health centre in Town C to treat suspected Ebola victims may be explained by the fact that he was poorly equipped, inadequately supported by formal health system structures and feared the potential violence reported against some healthcare workers. One respondent told us how an ambulance driver died from Ebola because one of the patients he was driving spat in his face saying *“I am going to die, you also are going to die”* (replacement Town Chief). Others threw vomit or faeces at them – and there were not enough PPEs to protect them.

In fact, there was only one ambulance in Moyamba District at this time. At the peak of Town C's outbreak it was assigned to the opposite end of the district, Ribbi Chiefdom, where an even larger outbreak was underway. Thus, moving known Ebola + patients to better equipped treatment centres was difficult, and many consequently died in the process. This context certainly continued to fuel fear of referral in Moyamba District until the opening of the Norwegian-assisted facility. According to the replacement Chief in Town C the overwhelming desire of many people to avoid testing and removal to the holding centre remained so powerful that it led to a group of mainly women and children trying to escape quarantine down river by boat, in a rainy season flood. The boat capsized and reportedly more than 20 were drowned: *“because they feared to be tested ... [replacement Town Chief]*.

In all there were around 24 Ebola deaths in Town C resulting from one family's understandable if misguided attempt to save their child, amid tensions between formal health system responders and townspeople fearing incarceration and cross-infection. As we have seen, however, order was eventually enforced and cooperation – albeit fraught – resumed in all these difficult cases.

4. Discussion: Actors, performance and (re)arranging systems of care

The cases presented in this paper show that practices and systems of care in Sierra Leone's epidemic response were shaped by complex, changing and sometimes unpredictable arrangements of hierarchies and actors, material considerations and wider historical and political contexts. Specifically, they demonstrate how arrangements of care in our case study sites evolved and intersected with the mainstream health system as relations between different kinds of authorities in each place evolved, profoundly shaping burial and care. The emergent Ebola-responsive health system was an example of “messy complexity”. Both anthropological and health systems scholarship recognise the importance of relational aspects of healthcare (e.g. Fairhead, 2014, 2016; Sheikh and Porter, 2011), but the international Ebola response failed to engage with these in practical terms. Rather, it focused on inputs of resources and protocols for the formal health system.

In contrast, understanding how new configurations of healthcare systems have emerged and enabling us to make better sense of complexity and ultimately understand how to shape more resilient health systems, requires, as Mary Douglas implies, telling new and complex stories about mutual dependencies and shared concerns (Douglas, 2007). Attention also needs to be focused on the mechanisms through which organizational templates bind with everyday practices (Richards, 2015).

“Agencement” can only be performed through relational engagement. This is where a neo-Durkheimian emphasis on quotidian ritual interaction (Collins 2004, 2008) may be helpful. Ebola was deadly and challenged the ways in which communities handled death. A key area of tension for Ebola responders was funerary arrangements; these needed to be re-arranged. An initial attempt by international responders to take this activity out of local hands met strong local pushback. The more local the burial team the better, since communities were strongly of the belief that only those who knew the victims in life should be in charge of the way they were buried. Meaningful interaction in ritual chain dynamics of “everyday encounters” (Enria, 2020) could not be bypassed, if collisions and tensions between co-existing systems of care and power relations were to be overcome.

Returning to our data, and our stories of how relations between multiple actors shaped burial and care practices, we consider whether and how artful methods of composition (Douglas) or arrangement (Deleuze & Guattari) were enacted in the process of rough-and-ready assembly of crisis-response, allowing us to see emergent order in “mess”.

4.1. Negotiating re-arrangements of burial and care

Burial was a core challenge in the Ebola response since it concentrated the biological hazard while at the same time remaining a social necessity for communities and their orderly continuation (Richards, 2016). The cases of the emergence of local burial teams in both Bo and Moyamba districts are clear examples of evolving arrangement at work. International responders sought to centralise the training and deployment of burial teams, in part because they feared the local infection-spreading emotional surge of funerals. WHO's initial attempt to create a protocol, from Geneva, on safe burials (WHO, 2014) was heavily criticised in the anthropological literature for lacking dignity and respect (e.g. Frankfurter, 2016; Martineau et al., 2017). It failed to address the social and spiritual dimensions of illness and death and risked being counter-productive (e.g. Fairhead, 2014; Chandler et al., 2015; Lipton 2017).

The Ebola Response Anthropology Platform helped reshape the international approach, supplying “real time” data and analysis on how the burial issue was playing out (Richards et al., 2015). Ethnographic work in Freetown has shown how *“burials became sites around which opposing “orders” were experienced, negotiated and reconciled in locally meaningful ways”* (Lipton, 2017: p.801). Neo-Durkheimian perspectives

shed light on how, in the case-studies above, ritual order was renegotiated, resulting in a reconciliation of approaches. Collins (2008), notes how armies control battle-field panic (historically, by musical means, such as beating a retreat). Similarly, ritual regulation of burial was achieved by town chiefs and local authorities demanding – and when they were not heeded, unilaterally enacting – that local people play a role in burial. This forced a rearrangement of burial practices. In Village A and Town C, delays in the arrival of centralised teams provided space to enact such rearrangements. Bodies could not be left on the street to rot. Local volunteer crews were established (though late on in Town C) to handle the grave digging even if only the trained crew from outside handled interment. These hybrid arrangements were eventually endorsed through incorporation in officially recognised revised burial rituals.

The importance of being able to provide food and water to the sick, as a social as well as a family need, was another clear point of re-composition in the narratives of resentment from Village A and Town C shaping people's actions. Such imperative to provide care has been widely reported elsewhere (e.g. Abramowitz et al., 2015; Chandler et al., 2015; Park and Akello, 2017). The holding centre at Moyamba was seen as an antithesis of this imperative, and people went to all lengths to avoid it – by both breaching quarantine (most shockingly illustrated in a mass drowning) and sequestering the sick in order to apply local treatments. This is best illustrated in Ribbi chiefdom (Parker et al., 2019a), the site of a prolonged outbreak.

After huge resistance from international responders, who denied the capacities of local carers (Oosterhoff and Wilkinson, 2015), it was eventually recognised that families needed to remain involved in care if prompt reporting and referral of the sick was to be achieved. This led to significant changes in official care arrangements. Homecare guidelines were published under the euphemism “Taking care of someone with suspected Ebola: be safe while you wait” (Richards, 2016).

Ultimately, there was a change in the arrangement of formal medical settings themselves as community care centres (CCC) were built to reinforce the specialist work of ETCs (Richards et al., 2019; Mokuwa and Maat, 2020). These CCCs were closer to communities and allowed families to bring food and messages to patients. They encouraged early reporting and rapid testing; and evidence exists to suggest they made a measurably important contribution to ending the epidemic (Pronyk et al., 2016; Mokuwa and Maat, 2020).

Finally, our cases show much evidence of complex interweaving of family and social connections with formal structures of public authority. Interactions between chieftaincies and representatives from health systems hierarchies) shaped renegotiations of authority and subsequent arrangements for burial and care. Confirming other scholarship (e.g. Bardosh et al., 2016; Wilkinson and Fairhead, 2017; Frankfurter et al., 2018; Parker et al., 2019a), our cases highlight how knowledge of historical and political contexts in which infection unfolds is critical to understanding how response “arrangements” have actually arisen.

In Village A, pre-existing cohesion in the district meant relationships between the district political leadership, health authorities and the chiefs, were cordial (reflecting effective co-operation during the civil war, 1991–2002). Trusted mutual engagement of powerful and potentially oppositional systems (different levels of chiefdom structures; district health and council authorities) meant that the experiences and actions of Village A were able to shape the formal Ebola response in important ways, most notably in opening up scope for local participation in safe burial team activity. This was not always the case elsewhere. In Town C a coalition of public authorities had to lobby, late in the epidemic, for their local burial team arrangements to be accepted. This was partly because district authority in Moyamba was less cohesive: historic alliances between authorities were more fragmented and authority contested at chiefdom and sub-chiefdom level. In Village B, initial hostilities between formal and community care systems over surveillance and reporting of cases (notably of the Chief's own illness) required a broker (an “arranger”). In this case (in the absence of the

ailing Chief's support for Ebola response) it was a respected paramount chief who brought about a negotiated settlement and enabled cooperation to emerge from chaos. In Town C, brokers of mutually accepted arrangements were harder to find, compromising public health responses.

Almost all the infected people and their families first sought care from CHOs or nurses, and post-Ebola, these professional cadres continue to play a key role in local disease surveillance. Their judgments and actions in remote locations, often without the support of professional second opinions, were at times crucial contributions to epidemic management.

4.2. Implications for healthcare systems response to crises

Three summary points can be distilled from this analysis. First, there are co-existing and hybrid practices or ‘systems of care’ (at family, town/chiefdom and district levels) which must be rapidly identified and coordinated (arranged) within the entangled health system. Entanglement is itself an historical process, and how practices have developed over time reflects a weight of history often unknown or underappreciated by newly arrived international health emergency responders. As we have shown, these care practices also evolved and changed in and through the response itself, requiring alert documentation to ensure a correct characterization of the health system as it emerges from crisis.

Nevertheless, family, social and health systems ordering, values and loyalties continue to collide, impeding coordinated crisis-responses. Managers operating within this fluid situation need, therefore, to learn rapidly from, and adapt to accommodate, social and family care systems. This may necessarily lead to reconfiguring care arrangements – even challenging entrenched national and international power hierarchies, as occurred in the establishment of local burial teams.

For researchers (and responders) this requires an understanding of a health system as relational web extending well beyond formal care settings. Multiple systems of care are entangled and the process of arrangement never stops. There is no perfect, static system. Interactions of healthcare users, providers and political leaders require constant compromise and flexibility. Therefore, the conventional term “health system” is too limiting for understanding the multiple, entangled arrangements of care that exist.

Second, our findings begin to identify some of the not always readily-apparent mechanisms through which the composition or arrangement of evolving healthcare systems is achieved. We have given examples of how mutually accepted healthcare arrangements were configured when institutions – or individuals – perceived as having “legitimacy in intimate spaces” (Parker et al., 2019b) acted as key brokers between conflicted parties. In our case studies, town, section, and paramount chiefs all played brokering roles where they held the respect of a majority of local inhabitants. Community Health Officers and community volunteers (not all of whom are unpaid), including local contact tracers and burial team members, also acted as brokers as well as providing critical health services during and after the epidemic (Vandi et al., 2017). While directly connected to formal health system responses (through reporting and – in theory – financial and logistic support), these community embedded cadres also have strong allegiance to their families and wider communities where they are based. Tsai et al. (2020) argue that this local embeddedness means they are vulnerable to local sanctions, but that this also makes them accountable, which then confers legitimacy on them as trusted interlocutors.

Our own analysis confirms the vulnerability of both CHOs and volunteer contact-tracers, and the significant challenges they faced, including death from disease (25 healthcare workers in Moyamba District died from Ebola: Elston et al., 2016). The importance of such cadres in fragile settings, and the frequency with which they are under-valued and not integrated within formal health systems and crisis-responses, is increasingly recognised (Hewlett and Hewlett, 2005; Martineau et al., 2017; Christensen et al., 2020; Raven et al., 2020). Health systems need

to better engage and support community responders (individual residents and leaders) and community-based health workers, both to value their local knowledge and their important role in maintaining critical contact between the community where they are embedded and formal healthcare responders. Enabling the agency of these 'first responders' to negotiate robust local protocols for infection identification, care and burial must go far beyond the development of external health responders' skills for community engagement as merely a practical tool to speed up population compliance with response measures. This risks the superficial "community engagement" evident in response to much of the 2018–2020 Ebola outbreak in the Democratic Republic of Congo (Mayhew et al., 2021).

Finally, resources play an important ancillary function in the negotiation of rearrangements of care. Our cases, however, confirm other work on how poorly equipped healthcare workers and facilities can undermine critical trust in formal health responses and put frontline health-workers including community-based staff and volunteers at risk of infection and stigmatisation (Hewlett and Hewlett, 2005; Vinck et al., 2019; Christensen et al., 2020; Raven et al., 2020).

We found that the lack of formal healthcare facilities for early outbreaks (Bo district) and continuing poor quality healthcare facilities (Moyamba district) contributed to fear of testing and referral and resentment of contact tracers, surveillance officers and other formal responders. This limitation was overcome, however, when new arrangements of actors emerged to negotiate for greater resources. In Bo district, health, council and chiefdom authorities collaborated to mobilise local funding and resources to support their response; in Moyamba individuals and coalitions negotiated support from international actors to improve their equipment and supplies.

This raises two big challenges for healthcare systems: first, how can rapid decentralisation of resources be achieved in emergency settings? Second, how might health systems be strengthened in the long-term to become more adaptable to and supportive of family-based and other under-recognised community systems of care? Increasingly, calls are made for longer-term commitment to strengthening local health systems and health-workers and improved flexibility of funding mechanisms that might allow for rapid decentralised mobilisation of resources (Cancedda et al., 2016; Martineau et al., 2017; Christensen et al., 2020).

In conclusion, achieving effective response mechanisms for health (and other) crises is of importance worldwide. The challenge for health systems responders is how to achieve timely, mutually negotiated, configurations of care practices that respond to local concerns and are effective. While previous research has focused on nationally-led Ebola responses which merely supported or obstructed local actions, our study shows that in fact local arrangements actually led and shaped a decentralised response from the outset. Through initial apparent chaos, the outbreaks we followed came under control relatively quickly (within three months). During these short periods, formal health systems actors, local chieftaincy actors and ordinary citizens were highly active in negotiating new accommodations. These arrangements inevitably involved compromise between formal and informal systems of care (moving a nurse; accepting quarantine) and sometimes reconfiguring power (by allowing local burial teams a greater role, or through overriding the actions of chief). Such efforts were themselves shaped by wider political and historical contexts and by the availability or lack of formal healthcare resources, which collectively help to explain why locally-led re-arrangements of care were more effective in some places than others.

The lesson of Ebola in Sierra Leone is that the response requires an approach to building systems and arrangements of care that extends well beyond the formal sector to encompass the agency of multiple first-responders from within affected communities. Health systems responders need to identify and engage with key brokers – or arrangers – in frontline care systems, with whom mutually acceptable, and effective, reconfigurations of care can be achieved. The subtle arts of the arranger are a key but neglected requirement to improve health systems

functioning during in an epidemic.

Author credit statements

Mayhew conceptualised this paper, led the analysis for this paper and was PI who led the funding acquisition, design, methods and investigation of the Ebola Gbalo study and wrote the original and final drafts of this paper. Balabanova was involved in data curation, formal analysis, funding acquisition, methods, investigation and writing. Vandi, Mokuwa and Hanson were involved in formal analysis, investigation, methods, validation, review and editing. Parker was involved in data curation, formal analysis, funding acquisition, methods, investigation, review and editing. Richards was involved in data curation, formal analysis, funding acquisition, methods, investigation, validation and writing.

Declarations

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