

Unpacking the Sociocultural Environment: Realities, Practices and Prevention of Disease Outbreaks in Uganda's Borderpoint Districts

ABSTRACT

Aim: The study was undertaken to deepen understanding of the community's knowledge, attitudes, practices and behaviours (KAPB) regarding epidemics.

Methods: This was a qualitative cross-sectional study conducted in four Ugandan border districts of Arua, Adjumani, Koboko and Kiryandongo. It used mixed methods and data were collected using observation, community dialogues, focus group discussions and key informant interviews.

Results: The porous nature of Uganda's border points and diversity of communities therein presents massive health system challenges in the prevention of and response to disease outbreaks. While some community KAPB might play a protective role, others are potentially harmful within the context of epidemics and demonstrate incongruence with disease facts or messages from disease experts.

Conclusion: We conclude that most community KAPB are entrenched in poverty, go beyond the scope of disease prevention or the health sector and call for concerted effort from across the political, geographical, social and economic divide. Approaches to community engagement in epidemic prevention and response should be cognizant of diversity and move beyond information dissemination to actually supporting behavioral change.

Keywords: [culture, epidemics, disease outbreak, community KAP, culture and health]

1. INTRODUCTION

Following Alma Ata's attempt to bring about common thinking around health systems globally in 1978 [1], the health systems of many countries were steadily improving the overall health status of the population [2-3]. This could be attributed to higher quality of and increased access to various health services [4]. However a number of epidemics have left devastating effects on many health systems - particularly those in developing countries - with political, social, and economic repercussions [5-6]. Currently most health systems around the world are ill prepared for epidemics due to new and re-emerging infections. Recent analyses undertaken argue that the Ebola crisis has highlighted an already known fact that many health systems do not have the means to respond to infectious disease outbreaks [7-8]. Numerous studies undertaken after Alma Atta showed the disproportionate burden brought by different epidemics for example Tuberculosis which became the leading cause of death among people infected with HIV, accounting for one-third of AIDS deaths worldwide in the 1990s [9]; cholera in Malawi and Peru [10-11]; meningitis in Burkina Faso [12] and the SARS epidemic which exposed weaknesses in the public health infrastructure of many countries, including inadequate state funding, lack of robust surveillance systems, severe

30 shortages in facilities and medical staff [6,13]. A recent study [14] on the Ebola outbreak in
31 West Africa found that several health-system functions generally considered essential were
32 not performing well and this hampered the development of a suitable and timely response.

33 The borderpoints of countries, especially those with politically or economically fragile
34 neighbours, are faced with daily influx of people which usually presents massive health
35 system challenges in prevention and management of disease outbreaks. This is worsened
36 by the fusion of diverse socio-cultural practices – some of which are in conflict with the very
37 principles of disease prevention. The Ebola epidemic unmistakably pointed out how
38 sociocultural beliefs and practices predetermine the onset, progression, control and
39 prevention of an epidemic. It is also in the wake of this crisis that researchers [such as 15-18]
40 have sought to understand this phenomenon.

41 **1.1 Epidemics in Uganda**

42 Uganda has experienced a number of disease outbreaks since 1971 [19] with the worst
43 recorded being Ebola in 2000 which claimed over 400 lives [20]. The country has also been
44 affected by similar viral hemorrhagic fevers like Crimean Congo, Yellow Fever and multiple
45 Marburg outbreaks including a recent one in 2014. The impact of these outbreaks has been
46 devastating as demonstrated by the plethora of evidence (see for example [21-25]. In all
47 cases of disease outbreaks, a national response team led by the Ministry of Health was
48 mounted with key partners like WHO, UNICEF and CDC with significant achievements
49 registered including improved health management information systems (HMIS) and stronger
50 surveillance network, strengthened laboratory capacity, better case management, capacity
51 building leading to skilled and experienced teams; established structures to handle
52 outbreaks and registering more political support among others ([19,26,27]. However this
53 national success story does not entirely apply to the local levels and particularly in the rural,
54 hard-to-reach or complex areas like borderpoints.

55 **1.2 Epidemics and the Sociocultural Environment**

56 WHO recommends that special attention is paid to the perceptions and traditional beliefs
57 about outbreaks when epidemiologic surveillance is being conducted [28]. Evidence on the
58 Ebola outbreak shows that traditional beliefs and medicinal practices play a big role in its
59 transmission [17] and that collaborations between the traditional and biomedical
60 understanding of illness are necessary [18]. A study conducted in Liberia [29] reported
61 funeral rituals and disparate gender roles as cultural aspects that shaped the progression of
62 the Ebola epidemic. In Uganda, many communities view illness through three lenses: the
63 spiritual, social and biomedical. The predominant view of a particular illness then determines
64 how it is treated and prevented [30].

65 While the evidence confirms the fundamental role played by a community's sociocultural
66 environment in disease outbreaks [29,15,16], globalisation has added another dimension to
67 these factors by making borders more porous and crossable for not only trade and other
68 human activities but also communicable diseases. In Uganda for example, many epidemics
69 have occurred within border districts like Kasese, Bundibugyo and Adjumani and these have
70 been complicated due to the different sociocultural dynamics at play. Sociocultural
71 knowledge and practices can exacerbate or play a protective role during disease outbreaks.
72 The strong linkages between health and local knowledge, attitudes, practices and
73 behaviours (KAPB) as well as the paucity of data on the diversity of sociocultural practices in
74 epidemic contexts were the rationale behind this study's objective to unpack the
75 sociocultural beliefs, practices and the role they play in the prevention and management of
76 epidemics. This paper presents part of the findings of a larger study conducted in 2015 to

77 assess the health sector's preparedness and response to disease outbreaks in four
78 Ugandan border districts. The study used both quantitative and qualitative approaches;
79 however the focus of this paper is on the qualitative objective "to deepen understanding of
80 the community's knowledge, attitudes, practices and behaviours (KAPB) regarding
81 epidemics".

82 **2. MATERIAL AND METHODS**

83
84 A mixed methods cross-sectional study was carried out in four Ugandan border districts of
85 Arua, Adjumani, Koboko and Kiryandongo. Data were collected using observation,
86 community dialogues, focus group discussions and key informant interviews. The study
87 population of 420 participants included health workers, community members; village health
88 teams (VHTs), opinion leaders and other key informants like district health teams (DHTs)
89 and Ministry of Health officials. Permissions were sought from the relevant authorities while
90 informed consent, confidentiality and anonymity of study participants was assured. Sampling
91 was done purposively with participant diversity and representation considered. Data
92 collection was both facility and community-based including in refugee camps; and study
93 participants represented about five countries in the Great Lakes Region including Uganda,
94 South Sudan, Congo, Burundi and Tanzania. Local interpreters were recruited and trained in
95 data collection and management procedures. Following fieldwork data were transcribed,
96 translated and thematically analyzed using NVivo 10 software.

98 99 **3. RESULTS AND DISCUSSION**

100 This study was partly an action research project where some feasible interventions were
101 implemented in response to the study findings - specifically the community's knowledge,
102 attitudes and practices. The key interventions in this regard included signposting
103 communities to existing health services and sensitisation in relation to uncovered knowledge
104 gaps and potentially harmful practices. The activities undertaken by the study team included
105 conducting community dialogues and health education/sensitisation using radio talkshows in
106 addition to engaging district and local leaders to find bespoke solutions to their local
107 problems.

108 Findings from the qualitative study objective on community KAPB are presented below. It is
109 important to note that although this is a results section, it is also inherently analytical in trying
110 to make sense of what the study participants were saying.

111

112 **3.1 Realities of Borderpoint Areas**

113 **3.1.2 Porous and high risk borders**

114 Ugandan border points are generally known to be porous and characterized by heavy
115 movement of people and goods on a daily basis. The findings of this study gave deeper
116 insight into this phenomenon – including drawing from community perspectives on the same.

117 Although the majority of study participants were Ugandans, neighboring countries (especially
118 South Sudan and DRC) also formed part of the respondents increasing participant diversity.
119 Despite obvious differences in nationality, community relations and networks were within and
120 beyond the borders. The diversity of community composition was revealed in some of the
121 responses such as from one of the local leaders below:

122 *Here in West Nile we have this thing called 'Sali ya Musala'. It means the three*
123 *cooking stones to put a pot and you need all the three stones because each one*
124 *serves a special purpose. So in 'Sali ya Musala' Uganda is here, Sudan there and*
125 *Congo – we have one leg in each country. We intermarry and most of the people*
126 *here have families and relatives across* (KI, Adjumani)

127 Many community members were found to live in oblivion or defiance to the notion of border
128 restrictions and instead try to focus on their biological and social ties as opposed to the
129 restrictions of geographical boundaries.

130 While confirming the heavy influx of nationals from other countries, many community
131 members reported its effect to be double-edged as shown in one response below:

132 *The Sudanese have indeed helped us here. You see for them they have dollars, so*
133 *they have no time to negotiate like our brothers here [Ugandans]... so business is*
134 *good when you are dealing with these people. When they come for market days*
135 *some of them bring bitenge [African fabric] which are real [authentic] and cheaper*
136 *than how they sell it in the shops and yet for our traders here we increase the price*
137 *but they [Sudanese] still buy* (Local leader, Koboko)

138 From the above excerpts it can be seen that open borders have contributed to economic
139 growth in the border towns as people from neighboring countries flocked into Uganda to buy
140 and sell different commodities. While foreigners entering Uganda for trading purposes did
141 not seem to pose a threat to local communities, it was those who chose to stay that were
142 causing tension.

143 In addition to scrambling for work and other limited resources, the conundrum of kinship
144 diversity was noted to make disease prevention and case management difficult, especially
145 within the context of epidemics. In fact study participants showed the risk that comes with
146 porous borders as illustrated below:

147 *The biggest problem here is that there are unnecessary crossovers. Let those*
148 *people also be screened because they just enter in and out of here with their*
149 *diseases as if it's a free toilet. Yet for us when we go to their side they say " that is a*
150 *Ugandan" and they chase us, arrest us or charge us [money] Our borders don't have*
151 *many restrictions like theirs* (Community member, Koboko)

152 *In Uganda we have a very established health system but we don't know the level of*
153 *their health services. Our statistics show that almost all epidemic index cases are*
154 *from across[other countries] which is an indicator that we are at different levels. And*
155 *this happens a lot because you cross any time you want without being checked and*
156 *it poses a problem because they carry all these diseases and our people suffer"*
157 (Healthworker, Adjumani)

158 The overall aim of the larger study was to assess the capacity of the health system to
159 respond to epidemics, and the excerpt above shows some of the system challenges
160 experienced. Even if health facilities were stocked with medicines and had sufficiently skilled
161 workers, the response to epidemics might not be entirely swift or effective because of the
162 nature of people and variations in health system capacity between neighbouring countries as
163 illustrated below:

164 *Here we can have response teams but there they don't have. In Sudan when we*
165 *had our cross border meeting we saw that the level of community engagement in*
166 *health is still very low. Even explaining things for their healthworkers takes a lot of*
167 *time, now imagine the ordinary people!* (DHT member, Koboko)

168 The excerpt above sheds some light on the system challenges and variations in capacity
169 across the borderpoints. It is clear that the difficulties in finding common ground among the
170 healthworkers and perceived differences in their skillsets make collaborative effort in
171 epidemic response more challenging than it should be. It also has a bearing on how
172 effectively communities can be mobilized for positive health action. The study found the
173 Ugandan population in borderpoint areas more aware of health dangers and demonstrating
174 better health-seeking behaviour compared to people from other countries who also lived in
175 these areas. This presented some health and ethical dilemmas for the healthworkers on the
176 Ugandan side trying to undertake disease prevention as seen below:

177 *The challenge is because we have three different communities and Uganda is now*
178 *better **healthwise** but people mix and intermarry so they have their brothers and*
179 *sisters across. This is a challenge we have and if epidemics become an issue, it*
180 *means interventions must be across. But you see our brothers across are lawless,*
181 *they do not listen to instructions and sometimes they cause a lot of chaos here*
182 *because they do not obey our rules (KI, Arua)*

183 *Those people ... I can't even call them refugees because they keep coming here*
184 *and going back. Sincerely they have a problem adhering to our health guidelines,*
185 *even for simple things like immunisation. So for us what we have decided to do is*
186 *time when there is a market day and then we go there to immunise their children by*
187 *force (DHT member, Koboko)*

188 The challenges experienced by the health teams at the borderpoints cannot be
189 underestimated, and could perhaps explain some of the extreme measures taken for
190 community health protection. It is extremely difficult for local health leaders to realize
191 population health when they did not have total control over people in their area of
192 jurisdiction. A number of factors add to the complexity including the porous nature of the
193 border, disparity in health system capacity and health awareness or behaviours across
194 different communities – some of which were described as lawless and non-compliant to
195 health regulation. These provide the backdrop against which health action, sometimes
196 unorthodox, has been taken.

197 In order to further mitigate potential health and security threats the community leadership
198 had introduced a system of identifying and tracking strangers as part of societal initiation.
199 This applied mainly to those people who settled in the community for a longer period of time
200 although visitors were also occasionally asked to identify themselves.

201 *When people come these days you ask them where they are from... whether they*
202 *have any diseases. If you are sick we link you to the hospital, especially if we see*
203 *that you are sick with visible signs like in the eyes... There are some other*
204 *sicknesses which we cannot see; so we ask "do you have such a kind of sickness*
205 *which normally disturbs you?" Then if you say yes we shall report to the health*
206 *center... most of them tell us the truth... maybe they want to take advantage of the*
207 *health facilities here so they declare their sickness. And those who are not sick we*
208 *give them resident IDs (Community leader, Koboko)*

209 The findings of this study confirmed what is already known that there are seasonal and
210 recurring epidemics which happen at specific periods in the year. This is particularly the
211 case for meningitis and cholera.

212 *Cholera is on and off. You find when there is lack of hygiene...it can break any time*
213 *even in the town council here it has ever happened. Even the meningitis belt is*

214 about to happen now, the time is close for it to strike us, in fact we are worried now
215 because this belt always hits us in the dry season (KI, Koboko)

216 Here in this [refugee] camp we have got cholera many times... it comes and goes
217 like after some time then it comes and goes again. We are used to it here

218 (Camp member, Kiryandongo)

219 Although the Ugandan population was noted to have generally higher levels of health
220 awareness, it was in relation to general health issues such as malaria, immunisation and
221 older or recurring epidemics as seen in the FGD excerpt below:

222 **Q: What do we know about these diseases?**

223 **CM1:** One time I was listening over the radio they were saying Hepatitis E spreads
224 through eating infected faeces and it affects the liver

225 **CM2:** It is also a viral disease which can destroy liver cells

226 **CM3:** Meningitis is an airborne disease because it is eating inside of the neck and
227 the others you inhale it

228 **CM4:** Hepatitis B is a viral disease that spreads through fecal-oral route. It is through
229 the mouth that is why it is fecal-oral I am just simplifying the answer for you

230 **CM5:** Hepatitis B you can also get it through sex

231 **CM6:** It [Hepatitis B] is a viral disease in which the urine has a cloudy colour and
232 also you bleed through nose and mouth

233 **CM4:** Hepatitis can be inherited so you can pass it on to your children

234 (Community FGD, Kiryandongo)

235 The sources of knowledge in regard to health issues included Ministry of Health adverts,
236 sensitisation during outreaches and information got from healthworkers at health facilities. In
237 spite of this however, there are still low levels of awareness about newer epidemics and
238 because most communities are superstitious, some diseases are linked to curses. Moreover
239 a lot of myths and questions were found to exist as seen below:

240 **Hepatitis B ... is another thing that is coming up. It's a big issue and we have lost**
241 **people because they don't know how to associate the transmission of Hepatitis B. It**
242 **is like HIV yet people here have bare [unprotected] sex, people touch body fluids like**
243 **blood and urine with bare hands. Because of ignorance we lost a teacher, our staff**
244 **here a fellow health worker and even we lost a police officer** (Healthworker,
245 Adjumani)

246 We know something about these common ones [diseases] like cholera and
247 meningitis unlike **Marburg**, Ebola, and Hepatitis B which are very new. We don't
248 know much about these ones, we sometimes hear things like they come through
249 grasshopper's wings. I don't know whether it is the truth or a lie that... Ebola for
250 example if it was in Sudan and if their grasshoppers fly here and you eat the
251 grasshoppers you can die of Ebola (Community Member, Arua)

252 *For Marburg here it is called silent “ndindia” and it kills humans and rats. It kills you*
253 *surprisingly until you get yourself finished. What I know is that when a rat gets it then*
254 *you can also easily get it. But for me what I want to know is if, for sure, monkeys*
255 *bring Ebola... I want to know the truth about Ebola. Those days when we went to*
256 *Congo they were eating monkeys and the belief for eating monkey was that when*
257 *you eat monkey the lady delivers very fast[childbirth] without a problem so they were*
258 *eating it because it helps the lady to give birth very fast. How comes that this Ebola*
259 *is associated to monkeys? Where do the monkeys get it from?* (Community
260 leader, Koboko)

261 Some community members seemed to hint at the perceived complacency or insufficient
262 effort of healthworkers at prevention or early stages of disease or in trying to dispel the
263 existing myths.

264 *In fact our major concern here is on Ebola, Hepatitis B and then Marburg but the*
265 *other diseases like cholera we know. Now what I would like is to first tell me how*
266 *those other diseases come and how can we avoid them? What I have found is that*
267 *you doctors first wait... most of us die of the disease and after is when they come*
268 *to give advice on what to do ... the good thing is to get advice early enough on how I*
269 *can protect myself.... We don't know where the diseases are originating from, how*
270 *we can prevent them, so we would like to know these but they [healthworkers] only*
271 *just come when we are dying* (Community member, Koboko)

272

273 **3.2 Local Knowledge, Attitudes and Practices (KAP) Accelerating Epidemic** 274 **Spread**

275 One of the most common practices found across the study area was **communal eating**,
276 which is where more than one person eats from the same dish/plate. Communal eating is a
277 cherished generation cultural practice among many communities and the study area was no
278 exception:

279 *Here we are all members of the same family, even with neighbours. We eat together*
280 *because we are one* (Community member, Arua)
281

282 *Our feeding nature is together [communal] and that is how it has always been in our*
283 *culture. We eat together... children and youth do not mix with adults during feeding*
284 *but strangers are not discriminated – they join and eat* (Local leader, Koboko)

285 Although culture and cohesion was the main explanation for communal eating, other
286 participants mentioned that lack of adequate food for households was also another
287 explanatory factor:

288 *For me what I can say is that the reason we put our food together especially for the*
289 *children is because it is little so when you start putting it on many plates our children*
290 *will see that it is little ... we make them to eat together so that they all finish together*
291 *at the same time instead of finishing and then just staring at the others*
292 (Community member, Kiryandongo camp)
293

294 Another key issue is **what communities actually eat**. This study found some community
295 diets to have the potential for disease spread. For example some communities were found to
296 eat monkeys and bats as can be seen in the excerpt below:

297 **Q:** What constitutes the local diet here?

298 **CM1:** Normal food like posho, beans and other things

299 **Q:** There are some **rumours** that some people eat monkeys, it is true?

300 **CM2:** Yes, **of course** we eat monkey meat... it is a delicacy here and even our great
301 grandfathers have been eating it. We keep hearing that it is dangerous but since our
302 ancestors no one has ever fallen sick from eating monkey meat so for us there is no
303 problem.

304 **Q:** Apart from monkey meat, is there anything else you eat that you've been told is
305 dangerous?

306 **CM3:** Okay maybe bats. Some people also eat that but you see they are different
307 types of bats – for eating and those which are not for eating. Even monkeys it's the
308 same, there are some types for eating and others which are not for eating

309 (Community FGD, Kigumba)

310 The excerpt above sheds light on the history, attitude and practice of the diet in question
311 which has implications for prevention and management of disease – particularly in relation to
312 some zoonotic diseases.

313 There were polarized views in regards to **handwashing**. While some community members
314 mentioned that they washed hands - albeit without soap - before eating, others said they
315 only washed after eating and not before. Key informants confirmed poor sanitation in the
316 community including the low hand washing levels:

317 *In terms of hygiene people here don't associate handwashing with health. Some three*
318 *years ago we did some study and found that only 17% of our communities here in*
319 *Koboko wash hands with soap after visiting the toilet* (KI, Koboko)

320 The reasons for low hand washing were varied and included the fact that most community
321 members did not think perceive their hands as dirty:

322 *People just think "If I have just been sitting here all day doing nothing like digging or*
323 *not touching dirty things, why should I wash my hands?" So they only wash if they*
324 *must like after eating food there you know that your hands are dirty*

325 (Community member, Adjumani)

326 Furthermore, some local and religious substitutes for proper hand washing have also
327 contributed to the prevailing poor hygiene. The most commonly cited impediment to
328 handwashing was religious practices, particularly among the Muslim community:

329 *Our brothers the moslems use "kibuyi" - that small bottle with water ... they enter*
330 *with it in the toilet and use it. That thing is an old cleansing material but it is now*
331 *regarded by moslems as a washing facility so they don't wash again after using it.*
332 *That "kibuyi" is something that has direct connection with epidemics so we still need*
333 *a lot of talking to our brothers and sisters the moslems; we are saying kibuyi is not a*
334 *hand washing facility - if you go there and use it, come outside and wash your hands*
335 *with soap* (KI, Koboko)

336 In addition was the practice of **open defecation** and **poor disposal of faeces** due to lack of
337 latrines in some homes. This had been countered by a campaign put in place by the DHTs to
338 eradicate open defecation:

339 *We have this ... community-led sanitation programme headed by the environmental*
340 *officer ... they have just received funds to go to the villages that can act as model,*
341 *those which have latrines. So the plan is to get the faeces out of Koboko... you get*
342 *your gloves, get the faeces and go to the community and show them "this is what*
343 *you are doing" to show the dangers. Even for the leaders, can you imagine some*
344 *leaders didn't have latrines? So naming and shaming is important, you say "LC in*
345 *this village you don't have a pit latrine where are you taking this amount of faeces in*
346 *a day and in a year?" When you mention all their names they are embarrassed and*
347 *tomorrow you will find they have constructed a latrine. This has really worked for us*
348 *(DHT member, Koboko)*

349 Related to the above, was the fact that **latrine proximity** was found to be located very close
350 to the living and cooking/eating areas:

351 *Our land itself is small, so where else can we construct the latrines? It still has to be*
352 *on our land so it is near the kitchen and flies can move easily from the toilet to the*
353 *food. Most people know it is dangerous, that is why we try to cover our food but*
354 *there is not much that can be done about it (Community member, Adjumani)*

355 **Poor sanitation and hygiene** was common in the border point areas. However, this needs
356 to be contextualized for better understanding and the statistics present a grim picture.
357 Individual and community practices can partly be explained by some structural barriers such
358 as low water coverage or drainage systems, high levels of poverty and limited levels of
359 awareness. For example according to key informants and district reports, at the time of this
360 study Koboko district had 41% literacy levels, 53% water coverage; 17% handwashing (with
361 soap) and 73% pit latrine coverage. This scenario is not very different in the other three
362 districts.

363 Another practice found was that people in some communities **shared accommodation with**
364 **animals**. The reasons for this were mainly fear of theft and also because some people just
365 loved their pets:

366 *Because of the location of this place some people choose to share accommodation*
367 *with animals. They don't want these animals to be stolen if you go to the rural setting*
368 *they fear thieves (KI, Arua)*

369 *People eat monkeys ... the Congolese bring these animals home as pets and enjoy*
370 *staying with them. There are others who even keep chimpanzees at home and*
371 *forget about vaccination at the veterinary department ... the fact is you enjoy seeing*
372 *the thing jumping, jumping but you don't know the dangers. The bird flu, do they*
373 *really think that you can have a problem when you sleep with the birds together?*
374 *They don't know because they put it under the bed. It is only when insects like small*
375 *ticks...begin to disturb entering their ears that they remove these birds out. So you*
376 *find in the village somebody is having the ear eaten off by this thing, then they come*
377 *for treatment ... so most of these behavioral things affect us in other emerging*
378 *diseases, they don't have knowledge... to understand this problem (KI, Koboko)*

379 One of the other deeply entrenched practices was **the way in which dead bodies were**
380 **handled**. Many communities at borderpoints were found to perform rituals following the

381 death of a loved one that could potentially be risky in disease outbreaks. This is illustrated in
382 the excerpt below:

383 *Q: What are some of the things this community treasures most?*

384 *CM1: For me I would say that we love our dead people*

385 *Q: Please could you tell me more about that?*

386 *CM2: He was saying that our culture treats the dead with respect*

387 *CM1: What I mean is that when someone dies, the dead body is washed very well*
388 *before burial and dressed well regardless of what killed the person. Here in our*
389 *culture we love the dead even more than the living.*

390 *Q: Who washes the dead body?*

391 *CM1: It is the women who wash*

392 *Q: How do they do it?*

393 *CM3: They just wash very well. Okay sometimes they don't have soap but they still*
394 *do it very well, like how you wash a young baby. So they wash and clean and dress*
395 *up the body*

396 *Q: Do they use any protective gear?*

397 *CM2: No they don't, they just wash. It is a way of paying our respect to the dead.*
398 *We wash them [dead bodies] and prepare to send them off.*

399 *Q: Oh, I see. So what happens after that?*

400 *CM1: So the dead person is mourned for a week or more depending ...older people*
401 *take longer... After that traditional investigations are done ... with the clan trying to*
402 *identify the cause of sickness after burial. This is called 'ancestral tracking'*
403 *(FGD with community members)*

404 Ancestral tracking was the community's form of epidemiology largely guided by cherished
405 cultural values such as the need to live in harmony with one's neighbor and pay back
406 whatever debt may be owed. This is especially if the leaders could link an individual's death
407 to an act or deed that needed to be done, after which it was believed that some form of
408 redemption would come. This is an interesting perspective and a positive one whose critical
409 timing [shortly after someone's death] and attitudes [when members are open to learning
410 lessons and acting in response] can be leveraged on by professionals seeking to improve
411 health outcomes in the context of disease outbreaks.

412 Other risky practices included drinking water from open surfaces and people living with
413 HIV/AIDS (PLWHA) sharing sharp instruments with others especially children.

414 **1.3 Institutional Measures**

415 In addition to the previously-mentioned institutional practices like forced immunisations for
416 foreigners, name-and-shame initiatives and sensitisation; there was also some multi-country
417 coordination effort with the World Health Organisation (WHO) taking the lead in addressing
418 health issues including epidemics during periodic meetings. Infact the effort of non-

419 governmental partners was praised as integral to the epidemic response effort at the
420 borderpoint areas:

421 *There are some government partners like UNICEF which is really demonstrating a*
422 *lot of interest in epidemics. Actually it is the one who told us to make a budget for*
423 *epidemic response and even gave us some money like 5million, otherwise before*
424 *that we had zero budget for epidemics. Also other NGOs come in to help here and*
425 *there but UNICEF is our biggest supporter in this* (DHT member, Koboko)

426 The threat of epidemics and response when it happens had, to some extent, been integrated
427 in existing systems and structures. This was especially true in the context of Uganda's
428 decentralized health system where there has been some effort to strengthen the referral
429 system from lower level health facilities upwards. Community health outreaches continue to
430 address key issues including disease prevention. In addition, training and capacity building
431 has been undertaken not only for the mainstream healthworkers but also for Village Health
432 Teams (VHTs), community leaders and other resourceful persons in the community who
433 have proven useful as can be seen in the excerpt below:

434 *A referral mechanism helps a lot when there is a problem ... I have a lot of trust in*
435 *these VHTs ... even the LCs [Local Council]. You know we had a case of meningitis*
436 *in Akuluba sub-county in Nyamwerere parish – that is near the border. But the way*
437 *the LC Chairman described the disease you would think he was an epidemiologist.*
438 *He called us and said "I have a disease here killing my people, many of them are old*
439 *people... not children, most of them are related by blood or they were together and*
440 *others have already gone to the witchdoctor. I have tried to keep away the members*
441 *who are not sick from those who are sick but it is not easy. Can you people come*
442 *and help address this problem?" So we have the potential within the lower people if*
443 *we can give them proper information and skills* (DHT member, Koboko)

444

445

446 **4. CONCLUSION AND RECOMMENDATIONS**

447

448 The findings of this study show the total sum of community knowledge, attitudes, practices
449 and behaviours (KAPB) to be double-edged. Some of these KAPB include high awareness
450 levels of old epidemic (94%) but limited knowledge of new and re-emerging diseases (33%);
451 washing dead bodies without protective gear (68%); poor sanitation practices (84%) and
452 risky diets (87%). While some KAPB might play a protective role, others are potentially
453 harmful especially within the context of disease outbreak. For instance the practice of
454 'ancestral tracking' where the community tries to investigate the possible cause of death or
455 harm of a member is one that has the potential of protecting the community – if understood,
456 supported and blended with scientific facts such as the basic tenets of epidemiology. The
457 community needs support to consolidate the protective KAPB and progressively discontinue
458 the harmful ones; this is not an easy or linear process – it will require a lot from both sides
459 and its complexity should not be underestimated. The aftermath of death is usually an
460 emotional and reflective time for the people involved; the inclusivity and critical timing that
461 'ancestral tracking' presents would be a good time to engage the community in regards to
462 disease outbreak, prevention and management.

463 Community KAPB demonstrate incongruence with the actual facts about different diseases.
464 This discrepancy calls for stakeholders seeking to intervene in disease prevention and
465 response to be sensitive especially to cherished cultural norms unlikely to change overnight.
466 While confident and keen to push their agenda, professionals will need to devote more time
467 to gain a deeper understanding of local cultural practices and the importance attached to

468 them. Although this issue has been highlighted by many anthropological studies, generally it
469 has not been in practice; in fact this rushed and non-negotiable approach by experts could
470 possibly explain why communities remain 'defiant' and continue engaging in their practices.
471 The relational landscape between health experts and community members needs to change;
472 this will require experts to move from seeing themselves as such but instead becoming more
473 of learners, facilitators and partners. Engaging the community as 'partners' needs to move
474 beyond rhetoric or tokenism to opening up the political, social and economic 'spaces' for
475 them to contribute meaningfully, be acknowledged, encouraged and celebrated in
476 mainstream disease prevention circles.

477 There is need to demystify the myths regarding different epidemics – this can be done with
478 continued sensitisation using various platforms such as community dialogues, radio talk
479 shows and health outreach programmes. However it is important for these education and
480 sensitisation initiatives to move beyond merely serving the purpose of information
481 dissemination to actually supporting behavioral change among community members with
482 bespoke strategies to achieve this outcome.

483 The findings of this study showed some community practices to be harmful and quick to
484 spread disease in the event of an outbreak, for instance washing dead bodies. In addition to
485 sensitizing communities about disease transmission and existing myths, this calls for further
486 thought and action from the experts. One of the ways this could be addressed is thinking
487 through and perhaps promoting the notion of access to and utilization of protective gear and
488 products at the community and household level. Tested and proven health campaigns for
489 example in HIV/AIDS, reproductive and family health have shown an increase in the
490 acceptance and use of protective products such as condoms and mosquito nets to reduce
491 infection. This same approach could be used in epidemics where communities are supported
492 to access and use protective gear and products such as gloves and sanitizers for example
493 when washing dead bodies. These approaches for community engagement in epidemic
494 prevention and response should not be one-size-fits-all but rather bespoke and cognizant of
495 diversity.

496 It is difficult to miss the fact that most of the harmful community practices and realities are
497 entrenched in poverty, for example that latrines are constructed close to the main house
498 while communal eating and poor hygiene is widespread. Beyond socioeconomic issues are
499 also those that are multi-sectoral for instance the community sharing accommodation with
500 animals for security issues and out of fear for theft which also has linkages with high levels
501 of unemployment. Another example is the reportedly lax regulations and restrictions at
502 Uganda's borderpoint areas. These issues go beyond the scope of disease prevention or the
503 health sector and call for concerted effort from across the political, geographical, social and
504 economic divide.

505 A considerable level of apathy and resignation regarding certain diseases was noted.
506 Particularly these are cholera (especially in refugee/camp settings) and meningitis in the
507 West Nile area. The resignation is as a result of various factors but mainly climatic variations
508 and the lack of sufficient resources, for example the meningitis belt occurs during the rainy
509 season and one of the districts leaders reported that for many years they did not have a
510 contingency budget for epidemics and that it is only in 2014 when one of the development
511 partners gave them five million shillings to put aside for this purposes – 5 million Uganda
512 Shillings (approximately \$1400) is a good start but it would not be sufficient to accomplish
513 much in the event of an outbreak.

514 Epidemic outbreaks in Uganda and elsewhere continue to demonstrate the critical need for
515 health system strengthening with serious attention paid to each of the health system building

516 blocks [3, 19, 31-32]. A systems-thinking approach especially at the planning phase needs to
517 be applied if health system strengthening is to be realized. This is in realisation of the fact
518 that, beyond epidemics, the health system should have the capacity to handle routine and
519 other health issues on a daily basis. Moreover some health conditions such as Hepatitis B
520 continue to increase in the face of limited access to treatment especially for adults in
521 accordance with current Ministry of Health (MoH) guidelines. A systems-thinking approach
522 will go beyond funding which as mentioned before is still insufficient but instead be holistic.
523 Furthermore, there is need to apply current debates on evolving health systems and how
524 they need to be people-centred [33-34]. Understanding and continuing to support MoH's
525 strides towards realizing optimal performance in regards to all the health system blocks will
526 be integral, as will the need for multisectoral and partnership working with all stakeholders.

527

528 **CONSENT (WHERE EVER APPLICABLE)**

529

530 Both authors declare that written informed consent was obtained from the study participants
531 for publication of this case report. A copy of the written consent is available for review by the
532 Editorial office/Chief Editor/Editorial Board members of this journal.

533

534

535 **ETHICAL APPROVAL (WHERE EVER APPLICABLE)**

536

537 The authors hereby declare that the study was examined and approved by the appropriate
538 ethics committee and have therefore been performed in accordance with the ethical
539 standards laid down in the 1964 Declaration of Helsinki.

540

541 **REFERENCES**

542

543 1. Harrington, J and Stuttaford, M Global Health and Human Rights: Legal and
544 Philosophical Perspectives. Routledge: 2010

545 2. Olmen, J, BrunoMarchal, B ,Van Damme, Kegels, G, and Hill, PS. Health systems
546 frameworks in their political context: framing divergent agendas. BMC Public Health 2012,
547 12:774 doi:10.1186/1471-2458-12-774

548 3. WHO Everybody's business: Strengthening health systems to improve health
549 outcomes. WHO's Framework for Action. Geneva: Switzerland. 2007

550 4. Tawfik, L. and Kinoti, S.N. The impact of HIV/AIDS on health systems and the
551 health workforce in sub-Saharan Africa. Support for Analysis and Research in Africa (SARA)
552 Project USAID, Bureau for Africa, Office of Sustainable Development. Washington:DC. 2003

553 5. World Bank. Confronting AIDS: Public Priorities in a Global Epidemic. Policy
554 Research Report. New York: Oxford University Press. 1999

555 6. Knobler, S., Mahmoud, A. and Lemon, S.,(Eds) Learning from SARS: Preparing for
556 the Next Disease Outbreak: Workshop Summary.Institute of Medicine (US) Forum on
557 Microbial Threats. Washington (DC): National Academies Press (US) 2004

558 7. WHO Guinea: The Ebola virus shows its tenacity, one year into the epidemic. WHO
559 Global Alert and Response. 2015

- 560 8. Bloom, G., MacGregor, H., McKenzie, A. and Sokpo, E. Strengthening Health
561 Systems for Resilience. IDS. [Online] 2015(Brief 18) Available from:
562 <https://www.ids.ac.uk/publication/strengthening-health-systems-for-resilience> [2/06/2015]
- 563 9. Raviglione M. C., Harries A. D., Msiska R., Wilkinson D., Nunn P. Tuberculosis and
564 HIV: Current Status in Africa. *AIDS*. 1997;11(Suppl. B):S115–23. [PubMed]
- 565 10. Swerdlow, D.L., Malenga,G., Beghokoyian,G., Nyangulu,D.,Toole,M.,
566 Waldman,R.J., Duhr,D.N.D. and Tauxe,R.V. Epidemic cholera among refugees in Malawi,
567 Africa: treatment and transmission. *Epidemiolol. Infect.* 1997. 118:207-214
- 568 11. Swerdlow, D.L., Mintz E.D., Rodriguez, M., Tejada, E., Ocampo, C., Espej,o L.,
569 Greene, K.D., Saldana, W., Seminario, L. and Tauxe, R.V. Waterborne transmission of
570 epidemic cholera in Trujillo, Peru: lessons for a continent at risk. *Lancet* 1992.
571 4;340(8810):28-33.
- 572 12. Plan (2010) Plan Burkina Faso fights meningitis outbreak. URL [https://plan-](https://plan-international.org/where-we-work/africa/burkina-faso/about-plan/news/plan-burkina-faso-fights-meningitis-outbreak/)
573 [international.org/where-we-work/africa/burkina-faso/about-plan/news/plan-burkina-faso-](https://plan-international.org/where-we-work/africa/burkina-faso/about-plan/news/plan-burkina-faso-fights-meningitis-outbreak/)
574 [fights-meningitis-outbreak/](https://plan-international.org/where-we-work/africa/burkina-faso/about-plan/news/plan-burkina-faso-fights-meningitis-outbreak/)Enserink M. (2003) SARS in China. China's missed chance.
575 *Science*. 2003;301(5631):294–6. [PubMed]
- 576 13. Kieny, M., David B Evans, B.B, Schmets, G. and Kadandale, S. Health-system
577 resilience: reflections on the Ebola crisis in western Africa.*Bulletin of the World Health*
578 *Organization* 2014. 92:850.
- 579 14. Hinshaw D. (2014) In Liberia, burial practices hinder battle against Ebola. *Wall street*
580 *Journal*.
- 581 15. Griggs M,B. The difficulty of burying Ebola's victims.*Smithsonian*.2014
- 582 16. Tambo. E. Understanding the Impact of AfricanTraditionalBeliefs,Customs and
583 Medicinal Practices on the Ebola Outbreak Crisis in West Africa. *Journal of Medicine and*
584 *Medical Sciences* 2014.Vol. 6(2) pp. 28-32.
- 585 17. Bah SM and Aljoudi AS. Taking a religious perspective to contain Ebola.*Lancet*.
586 2014 Sep. 13;384(9947):951.
- 587 18. Bwire G, Malimbo M, Makumbi I, Kagirita A, Wamala JF, Kalyebi P, Bingi A, Gitta S,
588 Mukanga D, Mengel M and Dahlke M. Cholera surveillance in Uganda: an analysis of
589 notifications for the years 2007-2011. *J Infect Dis.* (2013) 208 (suppl 1): S78-S85.
- 590 19. Uganda Ministry of Health website (2015) URL: <http://health.go.ug/mohweb/>
- 591 20. Mbonye, A.K. and Wamala,J.F. Ebola viral haemorrhagic disease outbreak in West
592 Africa- lessons from Uganda. *African Health Sciences* 2014. 14 (3) 496-501
- 593 21. Kinsman, J. A time of fear: Local, national and international responses to a large
594 Ebola outbreak in Uganda. *Globalisation& Health* 2012.Vol 18
- 595 22. Borchert, I. and Mutyaba Ebola haemorrhagic fever outbreak in Uganda: outbreak
596 description and lessons learned. *BMC Infectious Diseases* 2011.11:357

- 597 23. Okware, S.I. and Omaswa, F.G. An outbreak of Ebola in Uganda. Tropical Medicine
598 & International Health 2002 7(12): 1068-1075
- 599 24. Lane, J. and Nicoll, A. (2009) Outbreak of Ebola fever in Uganda officially over. Euro
600 Surveillance 5 (10): 1793
- 601 25. Kiwawulo, C. Uganda takes strides in handling epidemics. New Vision 30th July
602 2012.
- 603 26. Ssenkumbi, I. Marburg outbreak in Uganda September –November, 2012. Ministry of
604 Health.
- 605 27. World Health Organization. Protocol for the Evaluation of Epidemiological
606 Surveillance Systems. Geneva, Switzerland: WHO; 1997 (WHO/EMC/DIS/97.2).
- 607 28. Ravi S. J, and Gauldin E. M. Sociocultural dimensions of the Ebola virus disease
608 outbreak in Liberia. Mary Ann Libart, Inc. 2014. Vol 12, Number 6.
- 609 29. Hewlett B. S, & Amola. R.P. (2003) Cultural contexts of Ebola in Northern Uganda.
610 Emerging Infectious Diseases Volume 9. No. 10
- 611 30. Hafner T and Shiffman J: The emergence of global attention to health systems
612 strengthening. Health Policy & Planning 2012, 1-10.
- 613 31. WHO .Monitoring the Building Blocks of Health System: A handbook of indicators
614 and their measurement strategies. World Health Organization. 2010 Geneva: Switzerland
615 http://www.who.int/healthinfo/systems/WHO_MBHSS_2010_full_web.pdf. Accessed 28 May
616 2015
617
- 618 32. Sheikh, K., Ranson, M.K and Gilson, L. Explorations on people centredness in health
619 systems. Health Policy Planning 2014. 29 (suppl 2)
- 620 33. Mohga, K. Never Again: Building resilient health systems and learning from the
621 Ebola crisis. Oxfam International: ISBN 978-1-78077-848-8 2015