Original Research Article

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 and 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

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

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

1.1 Epidemics in Uganda

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

1.2 Epidemics and the Sociocultural Environment

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

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

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

2. MATERIAL AND METHODS

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

3. RESULTS AND DISCUSSION

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

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

3.1 Realities of Borderpoint Areas

3.1.2 Porous and high riskborders

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(Camp member, Kiryandongo*)*

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

Q: What do we know about these diseases?

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

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

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

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

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

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

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

(Community FGD, Kiryandongo)

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

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

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

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

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

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

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

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

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

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

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

For me what I can say is that the reason we put our food together especially for the children is because it is little so when you start putting it on many plates our children will see that it is little … we make them to eat together so that they all finish together at the same time instead of finishing and then just staring at the others

(Community member, Kiryandongo camp)

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

Q: *What constitutes the local diet here?*

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

Q: There are some rumors that some people eat monkeys, it is true?

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

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

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

(Community FGD, Kigumba)

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

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

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

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

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

(Community member, Adjumani)

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

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

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

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

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

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

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

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

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

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

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

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

> ***Q:*** *What are some of the things this community treasures most?*
>
> ***CM1:*** *For me I would say that we love our dead people*
>
> ***Q:*** *Please could you tell me more about that?*
>
> ***CM2:*** *He was saying that our culture treats the dead with respect*
>
> ***CM1:*** *What I mean is that when someone dies, the dead body is washed very well before burial and dressed well regardless of what killed the person. Here in our culture we love the dead even more than the living.*
>
> ***Q:*** *Who washes the dead body?*
>
> ***CM1:*** *It is the women who wash*
>
> ***Q:*** *How do they do it?*
>
> ***CM3:*** *They just wash very well. Okay sometimes they don't have soap but they still do it very well, like how you wash a young baby. So they wash and clean and dress up the body*
>
> ***Q:*** *Do they use any protective gear?*
>
> ***CM2:*** *No they don't, they just wash. It is a way of paying our respect to the dead. We wash them* [dead bodies] *and prepare to send them off.*
>
> ***Q:*** *Oh, I see. So what happens after that?*
>
> ***CM1:*** *So the dead person is mourned for a week or more depending …older people take longer… After that traditional investigations are done … with the clan trying to identify the cause of sickness after burial. This is called 'ancestral tracking'*
>
> (FGD with community members)

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

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

1.3 Institutional Measures

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

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

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

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

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

4. CONCLUSION AND RECOMMENDATIONS

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

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

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

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

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

It is difficult to miss the fact that most of the harmful community practices and realities are entrenched in poverty, for example that latrines are constructed close to the main house while communal eating and poor hygiene is widespread. Beyond socioeconomic issues are also those that are multi-sectoral for instance the community sharing accommodation with animals for security issues and out of fear for theft which also has linkages with high levels of unemployment. Another example is the reportedly lax regulations and restrictions at Uganda's borderpoint areas. These issues 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.

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

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

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

CONSENT (WHERE EVER APPLICABLE)

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

ETHICAL APPROVAL (WHERE EVER APPLICABLE)

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

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