

Exploring Perceptions and Recommendations Towards Initiating a Culturally Competent Ebola Response and Recovery



Minnesota African Task Force Against Ebola (MATFAE)
and Bloomington Public Health (BPH)/Public Health
Alliance of Bloomington, Edina and Richfield (PHABER)

About Bloomington Public Health/Public Health Alliance of Bloomington, Edina and Richfield

Bloomington Public Health (BPH) originated in 1948 to provide nursing services for Bloomington schools. In 1960 the agency was established as a community based public health division for the City of Bloomington. Since that time BPH has been providing health services and programs for Bloomington residents and employees. Beginning in 1977, BPH services were contracted by the cities of Richfield and Edina to provide public health services for their citizens, thus forming the Public Health Alliance of Bloomington, Edina and Richfield. In 2016, Bloomington Public Health/Public Health Alliance of Bloomington, Edina and Richfield were accredited together by the Public Health Accreditation Board.

For more information visit

<https://www.bloomingtonmn.gov/publichealth>

About the Minnesota African Task Force Against Ebola (MATFAE)

The Minnesota African Task Force Against Ebola (MATFAE) is a coordinated community-driven response to the impact of the Ebola epidemic. It comprises the leadership of the West African communities, especially Liberia, Guinea, and Sierra Leone. MATFAE also includes community-based African non-profit organizations, including African Immigrant Services (AIS), Liberian Health Initiative (LHI), faith-based groups, stakeholders, representatives of public institutions (Cities of Brooklyn Park and Brooklyn Center, Minnesota Department of Health, Hennepin County Public Health), among others. As the death toll of the worst Ebola epidemic gained worldwide attention, leaders of Minnesota's West African immigrant community gathered in the summer of 2014 to coordinate public support and awareness campaigns in Minnesota, as well as help with international medical and food relief for West Africa.

MATFAE has piloted a holistic community engagement and media response to the Ebola epidemic, becoming a nationally recognized model for coordinated community-driven solution and cross-sector collaboration, and elevated leadership roles of the African Diaspora on the US Ebola response. The impact of MATFAE's work are highlighted and featured in countless local, national and international media—Time Magazine, New York Times, NPR News, Al Jazeera, Bloomberg News, Associated Press, NBC News, CBS, Yahoo News, AllAfrica, FrontPage Africa, MPR News, Star Tribune, Minnpost, Pioneer Press, KSTP, etc. MATFAE has earned several awards and honorable mentions for its outstanding leadership role--both during and after the Ebola epidemic.

For more information visit

<http://www.kickebolaout.org/> | <https://www.facebook.com/MATFAE>

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Table of Contents



Executive Summary	3
Introduction	4
Scope and Justification of Project	4
Methods	5
Results	6
Recommendations	10
1. Cultural Competency	10
2. Mental Health Resources	11
3. Preparedness and Recovery Resources	12
4. Focus on the Future.....	12
Discussion	13
Conclusion.....	14
Bibliography	15
Appendix 1: Project Leaders and Organizations	18
Appendix 2: Geographic Depiction of Community Meeting Participants Based on Place of Residence	19
Appendix 3: Community Meeting 1 & 2 Notes	20

Executive Summary

Overview

The Ebola epidemic that occurred in parts of West Africa between December 2013 and April 2016 left catastrophic aftermaths on communities both in West Africa and the United States. Primary effects visible in Africa resulted in a perception of fear towards West Africans globally. The West African community was largely ostracized following the epidemic primarily due to an underlying culture in the United States of fear and misinformation in the media. Moreover, the crisis introduced new psychosocial issues that augmented or emphasized already underlying mental health issues and other pre-existing health disparities among the affected West African immigrants in various regions of the United States.

Partnership

The City of Bloomington (Minnesota) received funding to develop culturally-specific guidance on how to reduce stigma and lessen the emotional impact that Ebola caused in the West African Community in the U.S.; specifically in the Twin Cities metropolitan area in Minnesota. The City of Bloomington, acting through its Public Health Division (Bloomington Public Health (BPH)/Public Health Alliance of Bloomington, Edina and Richfield (PHABER) partnered with the Minnesota African Task Force Against Ebola (MATFAE), whose members represent West African countries impacted by Ebola, to co-create a process to gather input from the West African community on the psychosocial impacts the Ebola epidemic had on the community.

Objectives

The main objectives the project aimed to fulfill were:

- Provide technical assistance for psychosocial recovery within the West African population through collaboration between public health and local community leaders.
- Raise public health awareness about the impacts the Ebola epidemic had the West African community in the Twin Cities metropolitan area.
- Utilize participatory learning between community members and stakeholders to generate recommendations for best practices for emergency response and recovery efforts.

Process and Summary of Findings

The project was an assessment of the systemic challenges arising from issues surrounding the psychosocial effects of Ebola. Input from dialogue highlighting underlying systemic and psychosocial concerns with key informants from the impacted West African immigrant community was gathered during three focus groups and two large community meetings. Community meetings incorporated community-driven input derived from the focus groups. Participants brainstormed on potential best practices and solutions for recovery and preparedness with both community members, and stakeholder representatives from various government entities and organizations.

BPH/PHABER and MATFAE anticipate that the outcomes of this project will help reshape and streamline current response and recovery processes with culturally diverse communities in the Twin Cities metropolitan area. A consensus exists between community representatives and stakeholders that participated in this project on the value of instilling community driven emergency response and recovery efforts that are both collaborative and inclusive.

Introduction

The Ebola outbreak that occurred between December 2013 and April 2016 in parts of West Africa was the largest and most devastating Ebola outbreak in history, with approximately 28,616 cases and 11,310 deaths¹. The vast majority of the 17,306 Ebola survivors are in Guinea, Liberia, and Sierra Leone with a limited number of survivors in Italy, Mali, Nigeria, Senegal, Spain, the United Kingdom, and the United States of America¹. While these numbers provide a stark reminder of the horrific toll Ebola had on West Africa, measuring the impact is far more complicated. Each one of these cases and deaths is not just a number but represents a member of a family and a community. These survivors, their loved ones, and attending staff shoulder a burden that would be otherwise intolerable to most. The majority of cases were treated at an Ebola treatment facility with limited medical care despite the valiant efforts of local and international healthcare workers. They watched helplessly as friends and family died from Ebola in overwhelming numbers².

It has been reported that the isolation and stigma felt upon discharge from Ebola treatment centers often overshadowed the significance of surviving Ebola²⁻⁶. Staff working in the treatment centers experienced similar levels of mental distress as many struggled to process watching colleagues, friends and family die from a disease that overwhelmed healthcare⁷⁻⁹. Moreover, families of those who were sick and the survivors became ostracized in their community for fear of infection, complicating efforts to contain the disease and help the families recover¹⁰⁻¹². These primary impacts are what was most visible during the Ebola outbreak and contributed a perception of fear in West Africa and globally^{4,10,13-17}. West Africa had never experienced an Ebola outbreak before nor has there ever been an outbreak of this magnitude anywhere in the world. This new threat rapidly emerged and defeating it became a national and international priority.

Scope and Justification of Project

Minnesota is home to a large West African population, with the largest Liberian population in the United States¹⁸. As the cases of Ebola grew in West Africa, the fear, misinformation, and stigma this community suffered increased¹⁸⁻²⁰. In Minnesota, community members from the affected countries convened and founded an organization, the Minnesota African Task Force Against Ebola (MATFAE) in July, 2014. The task force is composed of community leaders and members from Guinea, Liberia, Sierra Leone, and other African nations. In addition to being a resilient support group, the taskforce took to

matters of addressing relevant issues with different health and local government entities including City, County, State and Federal leaders²¹. The City of Bloomington Public Health Division/Public Health Alliance of Bloomington, Edina, and Richfield (BPH/PHABER) began working with MATFAE in 2016 to identify ways to mitigate the psychosocial impacts of Ebola on the West African community. This partnership would allow BPH/PHABER to work at the grassroots level with MATFAE to mitigate stigma, and raise public health awareness about the impacts of Ebola on the West African Community in Bloomington, Edina, and Richfield, the cities in Hennepin County, Minnesota in which BPH/PHABER provides public health services, and the greater Twin Cities metropolitan area of Minnesota.

Methods

The project was carried out during a three month period between June and September 2016. This included several prep meetings between BPH/PHABER and MATFAE, three focus groups and two community meetings. Each focus group had approximately 10-25 participants recruited from the community by MATFAE. The first community meeting was attended by approximately 150 individuals, while the second had approximately 50 participants. BPH/PHABER and MATFAE jointly conceptualized the format of each meeting to ensure that the voice of the community was heard. Participants in the community meeting were recruited by both MATFAE and BPH/PHABER. MATFAE advertised the community meetings via local and social media outlets.

MATFAE advised against limiting the participation in focus groups to just residents of Bloomington, Edina and Richfield, as this would exclude many West African community members living outside of the selected cities. The focus became on ensuring inclusion of residents from Bloomington, Edina and Richfield, rather than restricting participation to just those communities. BPH worked closely with Hennepin County Human Services and Public Health staff during the planning phase as it was assumed most of the participants would reside in Hennepin County. It became clear during the focus groups that participants came from the greater Twin Cities metropolitan area (see Appendix 1 for geographical distribution of participants), which resulted in the public health preparedness coordinators from the greater Twin Cities metropolitan area being invited to participate in the community meetings. All focus groups and community meetings were held in Brooklyn Park, Minnesota as Brooklyn Park is home to and accessible to many West African community members.

For each focus group, a member of MATFAE was assigned as a community-based facilitator. Qualitative notes taken by BPH/PHABER staff in the focus groups, were compiled and analyzed by BPH/PHABER staff and MATFAE for common themes. Identified themes were used to structure the community meetings to gather recommendations for improvements to response and recovery efforts from both community members and stakeholders from various organizations in the Twin Cities metropolitan area.

Community meetings utilized small group discussions at tables with stakeholders and community members to transcribe and report out to the larger group recommendations for improvements to response and recovery efforts. MATFAE members were assigned to small groups to act as facilitators and note

takers. Recommendations were compiled and summarized by BPH/PHABER and MATFAE for the creation of this report. Audio or visual recordings were not used in focus groups or community meetings.

Limitations

A limitation of this study is the potential for members of the West African community to not have their perspective represented. While we heard from many members of the West African community, we did not have a systematic method for ensuring equal representation from the entire population in the Twin Cities metropolitan area. The community meetings also included a convenience sample of stakeholders such as public health agencies, local government and hospitals, but their participation was not representative of all stakeholders. This study has limitations due to the strong personal feelings community members had on the subject matter discussed. The themes and experiences reported by the community closely mirror results reported elsewhere on the topic^{6,16,22,23}.

Results

In focus group one, the meeting began with discussing the community's insight on how the Ebola epidemic affected them, someone they know, or the community as a whole. The scope of discussion ranged from stories that had taken place in West Africa or another country outside of the U.S. to experiences had in the Twin Cities metropolitan area. The stories highlighted the response process, coping mechanisms, and perpetuation of stigma individuals experienced. The community shared their overall sentiment regarding U.S. government, healthcare and other organizations' involvement and handling of their trauma and recovery from Ebola. An icebreaker question, "What does Ebola mean to you?" kindled a wide range of responses from both those directly affected or just heard about it. The main themes identified in focus group one focused on: Public health (and human services); Healthcare (hospitals); and Systems (defined as government agencies, institutions, non-government and international organizations, as well as the media).

In focus group two, the community discussed very frank opinions and sentiments regarding their feeling of being downplayed and let down by the healthcare industry. Major issues highlighted include:

- Cultural insensitivity through the stigmatization and discrimination by healthcare workers due to being from West Africa and the generalized association with Ebola.
- Lack of Information, Communication and Education on Ebola Traveler Monitoring
 - Several members of the community experienced discrimination in the work place as employers, unnecessarily forced individuals to stay home from work while being monitored for Ebola when the situation did not mandate it, based on fear of Ebola. People were told to go home until they were sure they did not have Ebola, which produced downstream consequences for many individuals.
 - The community felt that there was a lack of communication, education, and instruction by public health and healthcare providers about Ebola and more specifically, the Ebola

- traveler monitoring procedures (i.e. Ebola Phone). Many community members felt the voluntary monitoring program involuntarily quarantined them for 21 days, without any support for the financial or emotional costs which resulted.
- There was inconsistencies seen across the United States for how Ebola Traveler Monitor was utilized. With some high profile monitoring cases resulted in mandatory quarantine and the travel history of health care workers who became ill being heavily scrutinized.
 - Extreme Response to Ebola “Suspects”
 - Community members felt that when they went to receive treatment for an illness at a healthcare facility that the extreme response of healthcare workers putting on Ebola personal protective equipment based solely on their race/appearance, and/or travel history of being out of the county (not specifically to West Africa) was unjust and unnecessary.
 - There was a general feeling that interventions at healthcare facilities were geared at preventing further infection and did not take into consideration the traumatic effect such interventions may have on the individual or the consequences reflected onto the community.

Finally, in focus group three, the systemic issues were highlighted from community members’ viewpoints. Overall, the community had heartfelt sentiments about the ignorance about Africa as a whole by mainstream America. This, they felt, helped to perpetuate the immense fear that was widespread in the United States and their individual communities of work and residence during the traumatic Ebola epidemic. Issues highlighted were:

- Media Perpetuating Fear
 - Ignorance of Africa as a whole: America only knows bad things about Africa, or only bad things make it into the news about Africa.
 - Lack of education channels by the media about West Africa and the immigrant community.
 - Africa is a continent, not a country.
- Institutions and Agencies Downplaying the Issue
 - There was lack of international concern in the fact it took months after the crisis started for the World Health Organization (WHO) to announce it as a major public health epidemic.
 - The suffering of the community was largely ignored by institutions. The community felt their needs, specifically mental and psychosocial needs, were not met. Many individuals had to adjust routines in response to these needs and lack of support, such as dropping classes and missing work.
 - Some individuals were asked to stay home from work when travel to Africa occurred despite it not being to an area of widespread Ebola transmission.
 - The community felt that employers did not understand the magnitude of personal situations and/or were bound by employment policies that made it difficult for community members to take leave from work in order to cope with the tragedy.
 - Employment policies were not written to account for quarantine situations resulting in some individuals having to leave their job or being terminated from their positions because they were unable to show up for work due to being under quarantine for Ebola.

- Community felt ignored due to not being as ‘politically viable’ as other groups.
- Inadequate use of the community as a resource
 - Lack of a decision making hierarchy; intervention measures made and decided on by external organizations without involvement or consultation of leaders and representatives from affected communities.
 - Community was adamant on expertise about their own issues and would have preferred that programs and decision-making involved available leaders from the ground up.

Psychosocial Effects of Health and Systemic Issues Identified

An overarching theme in all focus groups was that of the psychosocial effects the Ebola epidemic has had on the West African community. Discussion in all three focus groups was largely centered on how the three themes identified (Public Health, Healthcare and Systems) affected psychosocial well-being and personal health. Several common themes, as expounded by the community, are listed below.

- Grief and Fear
 - Members of the community shared stories about emotional changes such as reoccurring nightmares, inability to grieve due to burial process, and uncertainty on how to move forward with life after this occurred. This traumatic experience also caused individuals to relive other traumatic experiences such as civil wars.
 - The community was adamant that infectious disease events will keep occurring and had a lingering paranoia of Ebola resurfacing in West Africa.
- Collapse of families/communities and culture
 - Death robbed many individuals of their loved ones; some community members reported tens of death attributed to Ebola in their families.
 - The decline of culture and traditional practices due to the need to dispose of bodies without cultural rituals, including proper burials had adverse psychological effects on most of the community members.
 - Some community members reported not knowing if their families were alive or where they would have been buried as mass graves were erected region- wide.
 - Locally, immigrant communities had to make changes away from identifying practices, such as wearing westernized clothing instead of traditional African outfits to prevent stigmatization and negative association with Ebola.
- Financial Burden
 - Travelling from West Africa during Ebola proved challenging with multiple ports of entry on alert. Community members recalled having to take multiple channels to return to the U.S. from affected regions. Travelling within Africa and other countries was also challenging and several business related trips had to be cancelled with significant financial implications for most.
 - Participants indicated loss of livelihood from closed businesses and even loss of employment due to the fear of the community during the epidemic.

- Many families have taken on the care and support of orphaned children (family or not) in West Africa by providing money and supplies. This added financial strain along with the emotional weight of the situation has left many feeling helpless.
- The Stigma of ‘Mental Health’ by the West African Community
 - Mental health is perceived negatively by the broader community. Within the community, the notion that it’s okay to be sick from the neck down, but not in your head creates feelings of isolation, anxiety, fear, and shame. This notion underlines barriers to appropriate care for this community.

Community Meetings

Representatives from public health departments, hospitals, and local and state government attended two large town hall style community meetings. Both stakeholders and the community engaged in interactive discussion towards alleviating the current trauma from the impacted community as well as future recommendations on a local and international level. Below are several of the common themes extracted from the community meetings; the full list of notes taken during the small group discussions at the two community meetings can be seen in Appendix 2.

- The West African community felt very strongly about the international community’s slow involvement and inability to fight Ebola.
- Many community members living in the U.S. experienced Ebola-related stigma for various reasons in various situations.
- In regards to emergency preparedness, including resources and education:
 - Need to strengthen the current health systems in affected countries in Africa in order to create resiliency and proper medical support.
 - Incorporate community-level education and outreach on sanitation and handling of cases.
- Rehabilitation and Trauma Recovery:
 - There was an appeal to both the local and international communities to take action on the part of every stakeholder. Valuable assistance wasn’t delivered due to the scope and array of resulting problems; however, improved coordination and understanding can resolve this.
- Culturally -Specific Response
 - Primary and secondary needs for health personnel and case management specifically tailored towards the impacted community were highly recommended. The community acknowledged the need for their own to be more involved in their own healthcare as personnel. They also called on other agencies and organizations to utilize available community groups and leaders to effectively facilitate cultural-sensitive outreach and mitigation.

Recommendations

It is evident from the stories and suggestions from the community that the recommendations for improvement do not fit into any one single theme identified in the first community meeting. They more suitably draw from each theme reinforcing the importance of education in the community, the response to an incident, and the overall cultural competency of the response and recovery efforts. The following recommendations were jointly developed by MATFAE and BPH/PHABER. It is our combined hope that these recommendations will be used to carry the discussion forward beyond this project to include future communities that may be impacted by an infectious disease public health emergency.

1. Cultural Competency¹

Responses to medical and public health threats need to be culturally appropriate. Incorporating cultural competency throughout the preparedness cycle should take a shift from planning *for* cultural groups to planning *with* cultural groups. This will require the pre-identification of key cultural groups in a community and recognizing leaders or bodies that represent those groups. Subsequently, response team need to develop or deepen relationships with those groups, and incorporate them into the preparedness cycle. The preparedness cycle includes five steps: plan, organize/equip, train, exercise, and, evaluate/improve. While some aspect of this already occur, a cultural responsibility in response is generally lacking. Preparedness planners need to work with partners and community liaisons who may have stronger connections to the cultural groups in your community and develop ongoing strong connections with the communities they represent through these collaborations.

Building such relationships and incorporation of cultural partners in the preparedness cycle will fundamentally change how cultural communities are considered during public health emergency responses. When our cultural partners are part of the planning process they have a voice in the values used to develop plans¹⁶. This deliberate process prior to an emergency will build trust in the community, help refine planning efforts to reflect the unique needs of the different cultures in our community, and provide a foundation for rapid community engagement during a public health emergency. A tangible process would be the incorporation of a known Community Liaisons position into the incident command structure of all emergency operation plans (EOP). This liaison should be considered a priority position to activate when need initially arises. This position would be a Subject Matter Expert under the Planning

¹ We follow the definition of culturally competent set forth by Cross, Bazron, Dennis, and Isaacs in 1989³⁷.

“The cultural competence model explored in this monograph is defined as a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or amongst professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations, The word culture is used because it implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group. The word competence is used because it implies having the capacity to function effectively. A culturally competent system of care acknowledges and incorporates- at all levels- the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally-unique needs.”

Chief engaging in discussion about appropriate response methods for the affected community and the proper modality to distribute information out to the public.

The owner of the EOP (i.e. Public Health, healthcare, other institution or entity) would be in charge of pre-identifying the appropriate individuals² or organizations within each culturally diverse community in their jurisdiction that could act as a Community Liaison. It is further recommended that the Community Liaison position be utilized in training drills and exercises conducted to become familiar with the notification procedures, incident command structure, agency/organization-specific protocols, and key job actions.

Such an inclusive use of Community Liaisons that can interface with government or healthcare authorities will allow for open communication channels that will lead to greater transparency between the community and respective organization. Consequently, the Liaison would be better equipped to provide accurate and appropriate information that can be delivered in a culturally responsive way to the community. Given the long duration of most public health emergencies, this approach is critical in maintaining trust and transparency with potential groups impacted by any emergency. This will help ensure public health messaging and the response strategies remain culturally specific as well as provide a venue for rapid feedback.

2. Mental Health Resources

It is pertinent to acknowledge the existing challenges towards mental health and contemporary medicine when ethnic cultures and minorities are concerned. A recurring theme in the focus groups and community meetings was the need for alternative resources to the conventional mental health. Members of the West African culture do not find it appropriate to discuss mental health, especially with someone without similar experiences to them. Underlying mistrust of medical practices, exacerbated by the stigma and discrimination felt during the Ebola crisis made many community members turn to their faith leaders, or other trusted community members for psychosocial support.

In order to support faith-based and other community leaders to provide psychosocial support to community members, public health and other healthcare authorities should provide psychological first aid training, and trauma-informed care training for faith and community leaders. These mental health resources will better equip faith and community leaders to support the psychosocial needs in their communities and for themselves.

However, psychological first aid training and trauma-informed care training may not be sufficient for all cases encountered. Therefore it is also recommended that Public Health and the healthcare sector work with relevant community leaders to better connect them with a variety of other psychological and social resources that they can utilize or refer to community members. To assist with knowing when to seek additional resources, it is recommended that mental health providers develop a guide for community leaders that provides an overview of their services, how they are obtained, and when someone should be referred to them. During a public health emergency, a process to help triage community members seeking

² A single individual is not recommended, rather multiple individuals (three deep methodology) representing the same community in order to ensure succession in the position.

support from community leaders needs to be developed in coordination with Community Liaisons and mental health professionals.

3. Preparedness and Recovery Resources

Public Health has a fundamental responsibility to provide the resources needed to effectively respond to the public health needs of the community before, during and after a public health emergency. The recommendations previously iterated are based on the perceived negative consequences observed by the West African community due to the slow global response to the Ebola crisis. Failing to respond to an incident in the infancy of the situation resulted in the Ebola crisis having a far-reaching and prolonged traumatic impact on West Africans around the globe. Though the Ebola crisis may have been declared to be over, a multitude of public health resources, including financial and technical assistance, are needed in West Africa to help rebuild, rehabilitate, educate and better prepare communities for any other catastrophe that might happen in the future.

In order to mitigate the vast impacts a crisis like Ebola has on a community, preparedness and recovery resources should be improved in developing countries around the world. The sustainability of preparedness programs relies on consistent funding that provides timely and effective resources needed by the community in need. Nonetheless, funding for emergency preparedness efforts has been on a declining trend making it increasingly difficult to combat public health emergencies, let alone prepare for them both locally and globally. Recovery efforts must include building the capacity of West-African-based organizations in the U.S. to enable them to collaborate with international organizations during response efforts in the region. A resilient community with a strong infrastructure will be more resistant to the impact of such disasters.

4. Focus on the Future

We will see another infectious disease public health emergency in the future. It is likely that another group will be impacted like the West African community was during Ebola. These recommendations may minimize the psychosocial impact to that community in the future if they are acted upon. These recommendations provide strong support for four of the six recommendations from the Presidential Commission for the Study of Bioethical Issues report on Ethics and Ebola: Public Health Planning and Response released in February 2015¹⁶:

“In an interconnected world, for ethical reasons and to protect national interests, the U.S. government has a responsibility to engage in preparedness and to participate in coordinated global responses to public health emergencies.”

“The United States should strengthen key elements of its domestic and global health emergency response capabilities. These include (1) strengthening the capacity of the World Health Organization to respond to global health emergencies through provision of increased funding and collaboration with other international, national, and nongovernmental public health organizations; (2) identifying and empowering a single U.S. health official accountable for all federal public

health emergency response activities, including both domestic and international; and (3) strengthening the deployment capabilities of the U.S. Public Health Service, including by streamlining command structure for deployment and by providing appropriate resources to train and maintain skills needed for emergency response.”

“Public officials have a responsibility to support public education and communication regarding the nature and justification of public health responses. Communication efforts should serve the following three interrelated purposes: (1) provide the public with useful, clear, accessible, and accurate information about the response, including what is known about what communities and individuals can do to protect their health; (2) provide those most directly affected by public health policies and programs with an appreciation of the values reflected in, and reasoning behind, their implementation; and (3) mitigate stigmatization and discrimination associated with many public health emergencies.”

“Governments and public health organizations should employ the least restrictive means necessary—on the basis of the best available scientific evidence—in implementing restrictive public health measures, such as quarantines and travel restrictions, intended to control infectious disease spread. In addition, governments and public health organizations should be prepared to communicate clearly the rationale for such measures and provide ongoing updates to the public about their implementation, with particular attention to the needs of those most directly affected.”

Having such similar recommendations highlights the need to work at the local and national level to protect communities impacted by public health emergencies. Based on the work that already occurred a group of interested community members and stakeholders will meet periodically to evaluate progress on these recommendations.

Discussion

Our findings highlight a (West African) community’s perception of neglect and under-service. These data mirror other reports that highlight a misinformation of Ebola knowledge and inadequacy of post-trauma service to such communities. West African communities faced an incredibly traumatic experience during the Ebola outbreak. This was trauma adding burden to ongoing recovery from civil war and violence and the impacts of poverty^{5,16,22}. Ebola frustrated the progress made in rebuilding the countries and communities as a whole. The secondary impacts on education, food, income, safety, and health of those living in Guinea, Liberia, and Sierra Leone have been profound and will have a long-term impact^{24–26}. These impacts are, to date, being experienced by West Africans living around the world, who provided support to their families and communities^{23,27}. Many of these individuals were not only supporting their families back home, processing the trauma of Ebola, but also dealing with stigma and fear where they lived around the world^{16,23,28}. Unfortunately, this phenomenon highlighted by this project

is not unique. Similar experience with stigma and fear have been encountered with previous Ebola outbreaks²⁹. One of the many lessons from the 1995 Kikwit Ebola outbreak in the Democratic Republic of the Congo was the need for psychosocial impacts to be addressed in patients that survived Ebola, their families and the medical staff that treated Ebola patients^{30,31}. This type of support was provided during the West Africa Ebola outbreak by NGOs but on a limited scale due to the overwhelming nature of the outbreak^{32,33}.

Traditional burial practices were linked to several clusters of cases, resulting in changes to burial practices to limit transmission of Ebola^{1,12}. Families that lost loved ones to Ebola thus lost a key component of their grieving process, traditional burial practices, which compounded the emotional trauma they experienced^{2,34}. Bereaved families' lack of closure by being unable to perform sacred traditional and religious rites and even, in most cases, not knowing whether loved ones survived being taken to an Ebola treatment facility or where they would have been buried resulted in significant psychosocial trauma³⁵. The media plays a critical role in health communication during critical times³⁶. Mass communication directly affects audience receptivity to public health information. Feedback received from both focus groups and community meeting participation highlights a correlation between media and stigma realized by those impacted.

Conclusion

MATFAE as an organization is still in existence and very much active despite the declaration of Ebola-free countries previously affected. Its leaders meet weekly to deliberate on ongoing recovery efforts and needs for their community members, both locally and abroad in their home countries in West Africa. They strive to assist the orphans of this tragedy, collect food and medical supplies to be distributed back home, work on policies to address relevant systemic issues such as employment, immigration and economic issues. There is a distinctive need to revise methods and expectations for engaging communities before, during and after an emergency that are both collaborative and inclusive. MATFAE and BPH/PHABER mutually aspire to draw attention to stakeholders towards shaping program operations tailored for this community and others that may be in similar situations in the future. We at BPH/PHABER hope to continue dialogue with our colleagues and other stakeholders towards constructive engagement with key stakeholders that will lead to enhancement of preparedness and recovery programs.

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Appendix 1: Project Leaders and Organizations

Minnesota African Task Force Against Ebola (MATFAE)

West African leaders and organizations that work on the Bloomington project (organized alphabetically)

African Immigrant Services (AIS)

- Abdullah Kiatamba
- Monica Habia

Guinea Community of Minnesota

- Hamady Seck

Liberian Health Initiative (LHI)

- Arthur Biah

Mualaynu Youth Initiative (MYI)

- Pastor Burleigh Holder

Masjid Al-Ansar Islamic Community Center

- Imam Mohammed Dukuly
- Fomba Konjan

Organization of Liberians in Minnesota (OLM)

- Mohammed A. Dukuly
- Mamadee B. Sesay

Sierra Leone Community in Minnesota (SLCM)

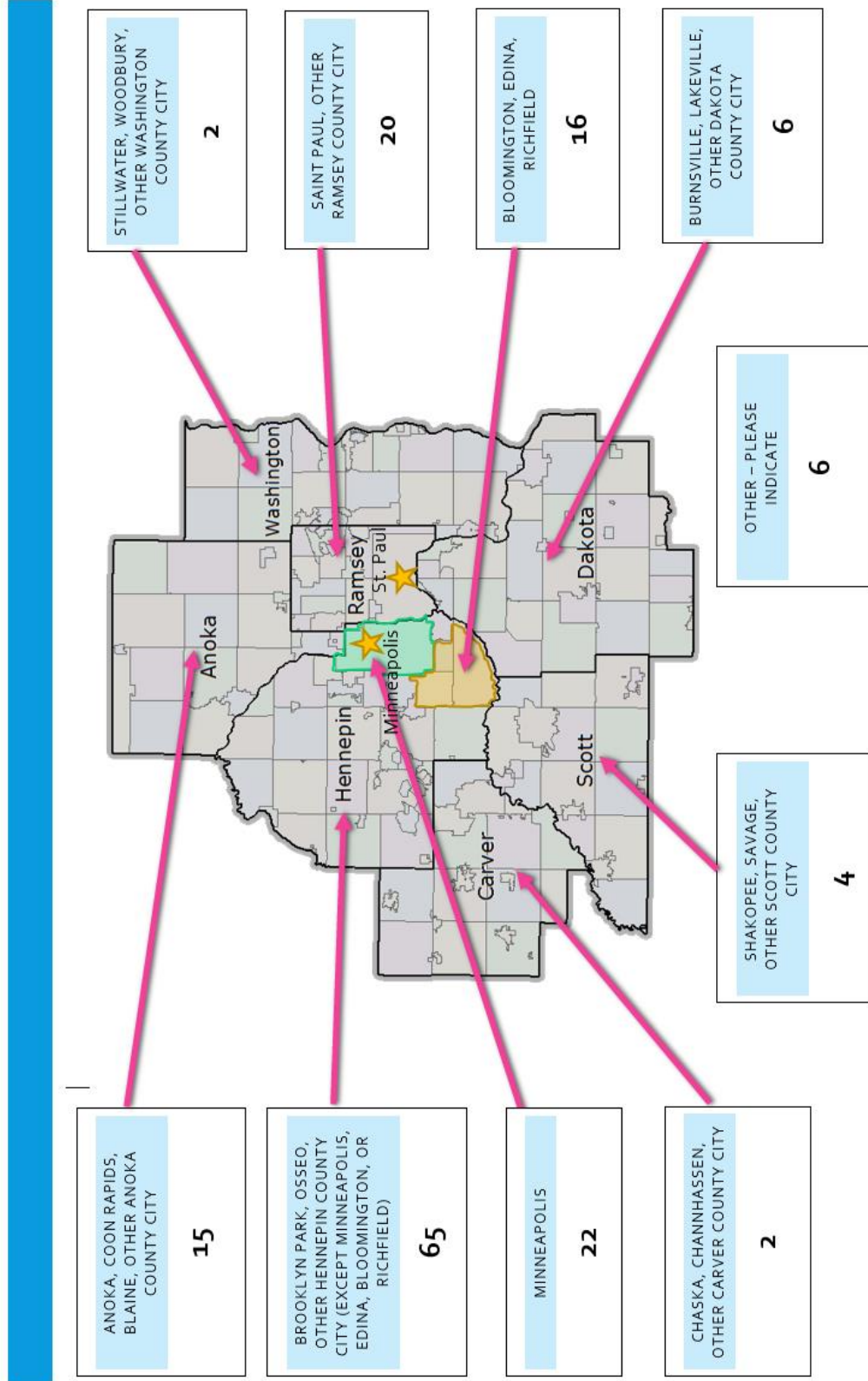
- Komba Fayia
- Karifa Jalloh
- Eizu Deen Shaw

City of Bloomington Division of Public Health/
Public Health Alliance of Bloomington Edina and Richfield

- Amanda Jeffy: Health Specialist: Emergency Preparedness
- Cynthia Jean-Baptiste: Health Specialist: Planner
- Nicholas Kelley: Assistant Public Health Administrator

Appendix 2: Geographic Depiction of Community Meeting Participants Based on Place of Residence

WHAT CITY DO YOU LIVE IN?



Appendix 3: Community Meeting 1 & 2 Notes

Education about Ebola

Community Meeting 1: Short & Long-Term Solutions	Community Meeting 2: Recommendations on What Could be Done Differently
Involve healthcare facilities, schools to create awareness of the disease	Information shared as education had a tone of fear. Didn't provide education in a way that treated other humans with dignity.
Educate West African community about hospital procedures and make sure that healthcare providers are explaining WHY they are doing something	Education was focused on myths more than the truth. Our community was not educated, but talked to and about. We have a close community, a resource for education that wasn't used.
Create an awareness in the community. Educate the public. Educate healthcare workers	Media has a huge challenge with understanding information about Ebola, especially when it came to culturally significant information. Reference to the St. Cloud Ebola meeting, when an expert tried to blame bush meat for the outbreak and asked the community what they did with bush meat.
Parents have to communicate with their kids	Cultural difference with education. There was too much focus on flyers and media. Come talk to us if you want us to know something
Educate community and healthcare professionals	Human behavior with crisis happens. People become agitated and increase tensions. How was that factored into the education?
Schools should be informed about the problem	Some people in our community don't read in our native language, so translations don't have the impact desired.
Much education will be required in every city about the effects of Ebola	Put the human touch back into education. There was not human follow up with our community. We got products, not education about the disease.
Parents to educate kids against stigmatizations in schools and how to respond	Fear factor killed the response. Educational messages came too late, especially on transmission. With all the fear, rational though was not common.
To create more awareness about the crisis	During a crisis healthcare authorities need to be transparent early and often about modes of transmission in order to better educate people.
Continue to educate people about proper hygiene (hand washing, etc.)	There needs to be training for those conducting the screening and quarantine process so that they do not react out of fear. This training should be conducted by the public health field - CDC or state agencies.

Educate the community about the Ebola crisis	Community facing agencies and institutions need to incorporate Trauma Informed Care training for all employees and annually offer refresher courses.
Enforce cultural competency training for medical providers	Community needs to work on the stigma around mental health - the community needs to understand that it is okay to seek help if you are experiencing mental illness.
Provide education	Better education on risk factors that are associated with health issues rather than discriminate the person.
Community leaders to continue to inform the public about the Ebola crisis	Propose education through the right channels and repeated avenues
School resources for students returning to school	Education should come more from the authorities with local input. Education was lost due to the media.
People not to live in denial	Culture is vital for education – lack of understanding of geography. Lots of examples of Africa being a country, not a continent. Fixing this is all of our responsibilities.
Too much fear was spread by the media	MN is getting more diverse and we need foundational understanding of other cultures so our state can move forward.
Messaging in the media needs to be controlled (improved) and education provided about the virus	Cultural competent staffing. Many places have members of our community on staff, but didn't use them for helping with the response. MDH supported organizations like the taskforce by investing in them.
Better communication and information sharing	Cultural organizations have leaders have reach into the community. They can share info with community on behalf of organizations. They are the cultural broker that need to be engaged. They also provide great insight into the response.
Educating the media (news reporters) so that they won't put fear into the listeners	Human resources/employee health can be a resource for health information
Provide communication methods and outlets	
Ebola was not thought of as a big sickness	
Let West African's educate other West Africans about issues here and back in Africa.	
Lack of communication	
School ground should be part of the community	

Response to Ebola

Community Meeting 1: Short & Long-Term Solutions	Community Meeting 2: Recommendations on What Could be Done Differently
Consistent use of questions in the clinic settings	There needs to be greater transparency between the community affected and the health authorities conducting the screening, quarantine or treatment of Ebola.
Knowing who to contact in our community; who are our leaders - we TRUST our leaders	There needs to be better communication with the media by all entities – use them as a partner to help in the response
Train healthcare workers	More in depth training needs to be provided to agents conducting the screening processes at the ports of entry into the U.S. as racial profiling was apparent.
Screening process - have you traveled to Liberia instead of have you traveled out of the country	Greater efforts needed to support orphanages, build/rebuild medical infrastructure back in Africa, and resources to help family members care for their families.
Infrastructure (medical) rebuilding	Resources for mental health training for the religious leaders knowing they will be the ones people will turn to for counseling and help.
Work to support the orphanages	Offer psychological first aid training in way that will not increase the negative stigma mental health has in the community.
Continue sending supplies and PPE to the region	There was a lack of counseling options for people in the community – it was not provided to the community like it has been for other tragedies.
Public funding for healthcare infrastructure	The community has not been engaged in drills and other emergency response activities before – community engagement with leaders of the community and healthcare/public health/other entities should take place early and often in order to better prepare for an emergency/crisis.
Need more health care providers from the community - need resources and ways to help achieve this	Local and international authorities were slow to act. Ebola was downplayed and not considered a major issue compared to Zika where the response has been huge and far-reaching.
Setup adoption programs to help orphans immigrate to the USA or elsewhere	Ebola protocols need to be revised in order to eliminate the racial profiling; special treatment of white Americans who contracted Ebola over those of color; and the stigmatization of an entire race ("you're black, therefore you must Ebola."). Screening protocols and quarantine measures added to the stigma and discrimination. There was unnecessary quarantine of those that did not even travel to the affected area.

Build infrastructure (healthcare) in developing countries	
Build better healthcare system	Essential services were often not provided to those in quarantine because it was unknown by health authorities that they were in quarantine.
Provide necessary treatment and logistics	Health authorities should partner with community leaders as soon as there is an issue in order to conduct a joint response.
Improve the health infrastructure of the affected communities.	Businesses need to have isolation and quarantine protocols that allow peoples' jobs who are in these situations to be protected
To have a place of budgets	Coordinate with community organization (MATFAE) to facilitate mental health training and education.
They should have a financial reserve for future response in terms of responding with adequate resources	Facilitate support/build capacity within the community and outside the community for attaining resources.
Africans themselves to raise funds monthly that they could save in the bank for future epidemics	There needs to be support from the health agencies for those in quarantine.
Even distribution of funding	There needs to be a collaboration between leaders of the community and healthcare authorities at the beginning of a crisis.
Lack of resources to empower organizations to pursue awareness campaign	Public Health Emergency Preparedness needs to understand and distribute information to the community that is culturally appropriate - just because people are from Africa doesn't mean there is a language issue, we need to collaborate with the community in order to disseminate the message appropriates.
Lack of resources	Faith-based leaders need to be trained in psychological first aid and other mental health techniques in order to help mitigate the psychological effects of the crisis. Knowing that people will utilize the faith leaders as trusted individuals, arming the faith leaders with the tools to help connect people with the appropriate resources will greatly help the community.
Work forces should have provided help	Healthcare authorities need to create a psychosocial screening process/algorithm that faith-based leaders can use to detect psychological issues/trauma in those that are coming to them for help and thus have more insight as to what that person may need in additional resources.
Provide ways and resources for people to contact such as community connections	There should be consistency in the level and way screening questions are asked. You cannot ask one person but not ask another. The way you ask

	someone is important in order not to re-traumatize someone or create more trauma for them.
Provide resources for how to care for family members	Health agency needs to support victims as opposed to acting through fear.
Mental health training for the religious leaders knowing they will be the ones people will turn to	Public Health authorities should work to identify community liaisons (not just West African) to engage in discussion when a situation arises in order to provide an appropriate response that is beneficial to the community largely effected and follows medical, ethical, and governing protocols.
Offer counseling	Educate
There was total lack of councilors due to the way in which the Ebola impact was underrated	Tackle the issue at the source. How patients got group was a challenge. Don't wait until it's a crisis.
Offer counselling as many people were psychologically traumatized	How do we develop policies that are equitable for response?
Provide counselling	
Health authorities were slow to act	
West Africa should have taken the front role in educating the community	
MDH was slow to connect with the affected communities [It should be noted that some community leaders also commended MDH's response and partnership during the same meeting]	
Quick response	
Lack of leadership	
A standing task force should have been put in place right from the start	
A task force to be set that would look into the overall handling of the past Ebola response in MN	
To be more proactive about the disease	
The negative impact of colonialism in African crisis response. It was discriminatory	
Lack of adequate international response	
Intervene early	
Provide temporary shelter for those coming into the country from Ebola countries over the 21 days of quarantine	
Global reaction (MDH, CDC) very slow	

Special treatment for white Americans who contracted Ebola - why was the same treatment not given to those of color?
Fix the disparity in response to Ebola vs. Zika
Compare Zika response to Ebola response
Offering assistance to the communities
Identify the roles in response for the state, schools, hospitals, etc.
Schools, Hospitals and Public Health need to include the communities in drills - weather, homeland security, emergency preparedness, infectious diseases
Engage with the community members and leaders early and often
Africans to be united and to stand for one another more than ever before
Collaborate with community leaders
Collaborate with community leaders
Get the community involved in the process
Workplaces should provide time off for workers
Have a treatment protocol in place at healthcare facilities
Test, test, test before judging. There needs to be a test done for Ebola immediately
Create better quarantine policies - even though some people had not been in the countries they were required to be quarantined for Ebola
Ebola protocols need to be revised - Ebola knows no boundary, global unnecessary quarantine of those that did not travel to affected areas
Task force to be set in every city
Effective leadership to be put in place
Effective leadership to be put in place for the long term
Schools to have a standby task force group who will provide counselling in case of future epidemic
They should invent/invest in quick Ebola testing tools that all households will have access to
Offer Psychological First Aid training in a way that will not increase the stigma of mental health

Cultural Awareness/Competence about West African Community

Community Meeting 1: Short & Long-Term Solutions	Community Meeting 2: Recommendations on What Could be Done Differently
Lack of community's educational effort of healthcare workers led to the stigmatization	All businesses (all sectors) should be required to provide cultural sensitivity training that is mandatory for all employees to attend. West Africans could provide this cultural sensitivity training/education.
Understand other cultures and how to best respond	Offer psychological first aid training in way that will not increase the stigma of mental health in the community.
Cultural sensitivity training in not only healthcare but businesses, governments, school, etc.	There needs to be a cultural liaison for hospitals (or anywhere) – communities could develop volunteer programs to assist with this, kind of like a medical interpreter.
Be better about showing empathy	Partner with faith communities and other non-profit humanitarian groups to help combat the negative messages with facts and cultural education.
Removal of fear through education of the community and outsiders about Ebola	Provide on-going education/outreach in communities around Minnesota about different African communities and other cultures.
Only people of color being asked if they travelled out of the country - need education about the process	Establish a liaison organization (i.e. MATFAE) with collaborate support of stakeholders (MDH).
Liberian communities assist in cultural competence for health care providers - help them learn more about the community	There has to be initiative, an effort to reach the community. MDH should have a database of community groups to reach out to for cultural connections. Need to have an intentional relationship with the community.
Ongoing education/outreach around different African Communities	Africa is not a country. A few countries in Africa don't represent the rest either.
Recruit and utilize advocates within the communities of color	Put money where your mouth is – back up statements with resources. Mental health and public health are always underfunded.
Healthcare providers should come to the community and listen to their experiences	Need a way to train/develop cultural leaders for response. This work won't happen unless it's funded.
Email/Tweet information/solutions on misconceptions of disease transfer after burial	Need to be intentional if we want to see cultural competency.
Education needed to help reduce the paranoia of citizens	Educate those responding. Do targeted outreach with cultural leaders in the community to media/government/decision makers. Understanding culture is important, our British heritage teaches us to remove threats. Prevention is not something we tend to think about. Understand how the community communicates and use those channels.

Cultural sensitivity/competence training	How do leaders model culturally responsive actions? They need to have a larger role in educating the community as leaders.
People did not understand Africa	Government can be very creative in how they support this work, they can provide space, platform, in kind support etc.
Stigmatization continues to this day	Public health Cultural competency training looks great on paper. How does cultural values transform your agency's work? The bigger the agency the hard this is.
The school system was never involved as stigmatized children continue to attend	
A lot of fear and hopelessness	
Negative comments	
Long-term engagement to reduce stigma around mental health and different health needs	
Give credit where credit is due, mention the heroic efforts of West African individuals	
Have a resident expert on Ebola in/around healthcare centers	
Include communities in drills for preparedness and infectious disease responses	
Getting solutions directly from the community	
Collaborate with all communities	
More partnerships with churches to help with emotional trauma in communities	
International communities - local leaders	
Utilization of local leaders by government agencies	
Cultural liaison for hospital partners - communities could develop volunteer programs to assist with this kind of like a medical interpreter	

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