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Refugee Viral Hepatitis Coalition of Georgia: An Assessment of Capacity Building

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REFUGEE VIRAL HEPATITIS COALITION OF GEORGIA: AN ASSESSMENT OF CAPACITY BUILDING

by

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APPROVAL PAGE

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ABSTRACT

Purpose:

The purpose of this project was to examine the process of capacity building through the formation of a coalition in Georgia to reduce the hepatitis burden in the refugee community. The project sought to identify obstacles in the building of the Refugee Viral Hepatitis Coalition to improve the effectiveness of the initiative. Observations were made in order to inform recommendations for future action.

Background:

There has been a significant decline in the number of hepatitis cases nationally and internationally due to the routine use of vaccines. However, there exists a significant number of cases each year, most of which have been identified in newly arrived refugees in the community. In the past five years, the majority of cases screened for hepatitis B have been identified among this population during screening exams at the local board of health. Public health officials in the state and county have identified many of the major gaps that lead to the persistence and transmission of infection in the community and have begun the process of building a coalition to address those needs.

Methods:

A mixed-methodological approach combining participant observations and semi-structured interviews was used to assess the formation of the coalition. Observations of the quarterly meetings took place from August 2013 to March 2014. Semi-structured interviews were conducted of coalition members within a four day period in order to gain insights about the progress of the coalition. Interviews were conducted in person and

over the telephone after an e-mail was sent to coalition members requesting their participation in a study to examine progress of the coalition.

Results:

Observations of the meetings showed that the coalition included community members, public health officials and members from a number of organizations that play a role in the health of refugees. Discussion topics included hepatitis B trends due to public health interventions, the Affordable Care Act and its impact on the refugee population in addition to the value of a support group for those living with hepatitis B. Seventeen members of the coalition were interviewed with a combination of in-person and telephone interviews. Answers were grouped into four themes which highlighted the motivation for the coalition, progress observed and recommendations for improvement of the coalition. Responses indicated that members were interested in improving awareness and treatment in the community, increasing formalization to promote growth of the coalition, increasing civic engagement and continuing to build on the strengths of the coalition.

Conclusion:

This study examined the process of coalition building to respond to the challenge of hepatitis B. Results indicated that members of the coalition play a role in the development of the coalition and influence the direction which it follows. The desire to continue on its current trajectory while improving formalization and recruitment efforts was expressed by members.

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CHAPTER I
INTRODUCTION

1.1 Background

As a result of their widespread use, hepatitis B vaccines have been successful in reducing the burden of hepatitis worldwide.[41] As the world's leading cause of hepatocellular carcinomas, the hepatitis B vaccine has been touted as one of the first vaccines to prevent a form of cancer and the first to prevent a sexually transmitted disease.[28] Nations with high endemicity of hepatitis have been able to decrease significantly the rates in deaths due to liver cancer and other morbidities associated with hepatitis B. In fact, the United States has experienced a 94 percent decline in hepatitis in persons under the age of 20 years from 1990 to 2004 alone[1].

However, there still exists a significant burden of hepatitis B. In Georgia, the majority of new infections are identified among newly arriving refugees. A number of challenges such as language barriers, adapting to a new culture and lack of familiarity with the healthcare system make it difficult for refugees to obtain needed care. These challenges lead to inefficiencies in the linkage to care as many gaps are present in the screening to treatment pathway.[43] The Refugee Viral Hepatitis Coalition was initiated in 2013 in order to eliminate these challenges.

Globally, there are approximately 350 million persons living with chronic hepatitis B virus (HBV) infection and 7,844 cases reported of acute Hepatitis B. Approximately 666,000 persons die annually from HBV–related liver disease.[26] The United States Centers for Disease Control and Prevention estimates that 4.4 million Americans are living with hepatitis and are unaware of their status.[42] Hepatitis B is a reportable condition in Georgia and cases are to be reported to a local health department within seven days of diagnosis. Without proper

identification and treatment of cases, the disease remains prevalent in the community and can be transmitted to others.

Routine screening at the local health deparement helps to identify a number of health conditions such as hepatitis B. Each year, roughly 2,000 to 3,000 refugees are screened for Hepatitis B at the local board of health. Identification of cases is important as the risk of liver cancer is 12 to 300 times greater in individuals chronically infected with HBV than in those who are without the infection.[2] The virus induces disease by attacking the liver which can lead to liver cancer and cirrhosis if poorly managed. High endemic areas for hepatitis B include: Southeast Asia, the Pacific Basin (excluding Japan, Australia, and New Zealand), sub-Saharan Africa, the Amazon Basin, parts of the Middle East, central Asia republics, and some countries in Eastern Europe. Hepatitis B prevalence is highest in sub-Saharan Africa and East Asia. The countries in which hepatitis B is an endemic virus more likely to be poor, making it difficult to afford vaccines or modern treatment.[27] As a result, the condition of hepatitis is more prevalent in refugees from these endemic regions.

Most refugees to Georgia come from South East Asia, Eastern Europe, Middle East and African. The seven counties that are part of the Atlanta metropolitan area are home to the majority of refugees. This influx has contributed significantly to its cultural diversity, with the addition of new social norms, languages and belief systems. Many refugees reside in communities such as Clarkston, Decatur and Chamblee, creating a unique cultural mix.

Upon arrival in the county, new entrants are required to get screened at the local health department. After screening they are given referrals to obtain care at other facilities and agencies if further testing or treatment is necessary. However health workers recognize that the system does not work well at times and have identified the need for better coordination.

Coalitions have served as useful tools to address inefficiencies that exist in the delivery of care. Among the challenges faced by refugees are language barriers, logistical issues such as transportation to get treatment, loss of follow-up when refugees move to a state without sister agencies, as well as providers inadequately equipped to handle the challenges of working with refugees. The Refugee Viral Hepatitis Coalition aims to eliminate these challenges by bringing together entities that normally do not interface to come up with lasting solutions.

1.2 Purpose of Study

The purpose of this research was to examine the formation of the Refugee Viral Hepatitis Coalition in Georgia, in order to provide recommendations for improvement of its development. The use of semi-structured interviews and participant observations allows for examination of the viewpoints of coalition members in order to gain insights about common themes and beliefs about the effectiveness of the coalition.

1.3 Research Questions

1. How has the coalition building process in Georgia fared in meeting its initial goal of reducing the burden of hepatitis B in the community?
2. Do the members in a coalition shape the evolution of the coalition? If so, how?
3. How do members of the coalition perceive the progress of the coalition?

4. What recommendations can be made to improve the effectiveness of the coalition?

CHAPTER II
LITERATURE REVIEW

The purpose of the study is to examine the formation and effectiveness of the Refugee Viral Hepatitis Coalition in Georgia. The following is an overview of coalitions, the burden of hepatitis and trends in refugee health.

2.1 Definition of a Coalition

A coalition is defined as an organization of diverse interest groups that combine their human and material resources to effect a specific change the members are unable to bring about independently.[7] They are inter-organizational, cooperative, and synergistic alliances uniting individuals and groups in a shared purpose.[6] They have also been described as multi-purpose alliances which direct their interventions at multiple levels such as policy change, resource development, and ecological change.[8] When used as intervention strategies in the field of public health, the need for coalitions to be maintained and remain durable over extended periods of time becomes evident. This is particularly true as modifying chronic conditions and their social causes is a long-term enterprise that requires normative change.[9]

Coalitions as vehicles for health promotion have been utilized as a public health strategy[3]. They serve a number of goals and may include a number of diverse entities working collaboratively to achieve a particular aim. There is extensive literature about the use of coalitions in promoting public health goals. However, documentation about these interventions is limited due primarily to challenges in utilizing most traditional methods of evaluation.[4,5]

Coalitions have been utilized in alleviating community challenges such as gun violence, asthma in children, and the spread of infectious diseases.[6] Their stage of development and

function are interrelated as the stage of development typically dictates the function of the organization. [6]

Coalitions are important in achieving public health goals since they can be utilized to build community and organizational support to respond to an unmet community need. First, coalitions can enable organizations to become involved in new and broad issues without having the sole responsibility for managing or developing those issues.[10] This allows the organizations to dedicate energy to participate in other activities of value without jeopardizing their primary duties. Second, they can develop and demonstrate widespread public support for issues, actions, or unmet needs.[6] By bringing together entities that have a stake in meeting an unmet need, the community as a whole can gain greater awareness of the issue and have an opportunity to get involved. A synergy is created that is greater than the entities working independently. Third, coalitions can minimize duplication of efforts and services by improving trust and communication among groups that would normally be competing with each other. This can lead to economies of scale as the investment by each member in the coalition can potentially be reduced.[11] Fourth, coalitions can help mobilize more talents and resources to influence an issue than any single organization could achieve alone through leveraging the strengths of the constituent members.[3]

2.2 Classification of Coalitions

Coalitions are categorized based on a number of factors such as membership, size, patterns of formation, functions, and organizational structure.[6] Patterns of formation have been utilized to categorize coalitions.[11] Many times they form in response to an opportunity or threat.[12] Coalitions can be categorized based on size and can range from a few individuals or

organizations to hundreds of persons.[13] Coalitions can be categorized based on membership such as professional coalitions, grassroots coalitions as well as community based coalitions. Professional organizations are formed at a time of crisis or as a long-term response to increasing their power and influence.[11]

The function of a coalition is another way in which coalitions are classified. Since members of coalitions may differ in their ideologies and resources needs, coalitions may differ in the various functions they have for the different organizations involved. Members may be interested in information and resource sharing, technical assistance, planning and coordinating of services and advocacy.[14] Coalitions for health promotion and disease prevention perform often functions within more than one of these categories.[6]

2.3 Coalition Development & Evaluation

While there is no consensus on the stages of coalition development, researchers agree that common activities occur over the lifespan of a coalition, including recruiting, mobilizing members, establishing organizational structure, building capacity, planning for action, implementing of strategies, evaluating outcomes, and institutionalizing strategies.[15] Thus, as coalitions develop in stages, discourse on coalition functioning necessarily takes into account a coalition's level of development. Factors likely to improve functioning at any particular stage are best informed by knowledge of a coalition's position along a continuum. It is important to note that these stages are not mutually exclusive nor always clearly designated as there exists areas of overlap in function.[6]

During the initial stage of a coalition's formation, the most important element is the articulation of a clear mission or guiding purpose for the coalition.[16] This occurs when potential members reconcile the pursuit of individual goals with a sense of common purpose.[6] This

cooperation at the formation stage appears to be a vital component in helping the coalition to be cohesive and effective.[17] The process of bringing the potential member agencies together around a central focus is usually catalyzed by the lead agencies in the coalition-building process.[18] In order for collaboration to occur, potential member organizations must believe that collaboration will produce positive outcomes.[19] At this stage of coalition development, activities aimed at increasing collaboration among the members will assist in working to achieve a central mission.

Formalization of the coalition allows for the development of an organizational climate and relationships with external supports.[6] As collaborative endeavors, the relationships that are created are a coalition's most useful asset.[20] The greater the degree of formalization, the more likely member agencies will be responsible and committed.[21] Examples of formalization include clearly defined mission statement, goals and objectives and written policy and procedure manuals, as well as clearly defined roles.[22] Formalization increases the implementation of the coalition's operations and the process of making the activities routine, improving the likelihood that the coalition will be sustained.[6]

Strong central leadership is essential in the implementation and maintenance of a coalition.[23] Irrespective of size, there is a tendency for a few core leaders to dominate coalition activities.[24] Core members of a coalition are found to be key to initial success.[25]

Evaluation of Coalitions. Evaluating the effectiveness of a coalition is essential in maintaining the continued support of community as well as that of funders.[20] Measurement of the long-term effects of coalitions is limited in the literature.[4,6] Much of this dearth of evidence is due to challenges with the evaluation of coalitions as traditional scientific methodology is poorly suited for capturing fine-grained coalition outcomes.[4]

Recent efforts at evaluating coalitions include the Community-Based Participatory Evaluation (CBPE) method. This allows members greater access to create organizational and community change by increasing the capacity to collaborate. However, the most significant challenge in utilizing the CBPE approach includes factors of cost, time and the need for skilled evaluator knowledgeable of all aspects of coalition work.[20]

2.4 Hepatitis

Hepatitis is the inflammation of the liver and is often attributed to viral infection. There are five main types of hepatitis A, B, C, D and E, referred to as – HAV, HBV, HCV, HDV and HEV, respectively. Types B and C lead to chronic disease in hundreds of millions of people and, together, are the most common cause of liver cirrhosis and cancer. It is estimated that more than 2 billion people are infected with hepatitis B worldwide. Of this figure, 360 million are estimated to have chronic hepatitis and are at risk of serious illness and death mainly from cirrhosis and hepatocellular carcinomas. Each year, nearly 600,000 HBV related deaths occur worldwide.[26]

Refugees from areas of high HBV endemicity such as Asia, the Pacific Islands, sub-Saharan Africa, the Amazon Basin, Eastern Europe and the Middle East are considered high risk. Children born in the United States to refugees from areas of high HBV endemicity are also at an elevated risk. Among the groups with the highest risk are infants born to mothers who are positive for the Hepatitis B surface antigen. The risk for becoming chronically infected with HBV is between 2 to 6 percent of older children and adults, 20 to 50 percent of children under 5 years of age, 85 to 90 percent of infants infected at birth, with a peak incidence in 40 to 60 year olds.[43] In Taiwan, the number one cause of death for men over 40 years is liver cancer due to hepatitis B.[28] Over 1500 persons die each year in the U.S. from hepatocellular carcinomas (HCC) which is four times more common in HBsAg+ men than women.

Transmission. Humans are the only reservoir for HBV. The hepatitis B virus can survive outside the body for at least seven days, during which the virus can cause infection if it enters the body of a person who is not protected by the vaccine.[27] This virus is transmitted percutaneously and via permucosal exposure of infected blood and body fluids, mainly semen and vaginal fluid. The highest concentrations of infectious HBV are found in blood and serum.[28] The incubation period may vary from 30 to 180 days, but on average tends to be closer to 75 days. The surface antigen of HBV (HBsAg) may be detected in serum 30 to 60 days post infection and persist for variable periods of time. Roughly seven to forty percent of those with a positive HBsAg may also have a positive HBeAg (hepatitis B e-antigen) which is associated with high infectivity.

The global epidemiology of HBV is commonly described according to three categories – high, intermediate and low endemicity. The majority of children born to HBeAg mothers become chronically infected unless vaccinated at birth. In areas where HBV is endemic, perinatal transmission and person-to-person transmission in early childhood are the most common form of transmission. In areas of low endemicity, perinatal transmission may account for one third of transmissions. Sexual transmission and the use of contaminated needles account for the majority of transmissions in regions of low endemicity.[28, 26]

Vaccination Significant declines in hepatitis B infection in areas of high endemicity have been observed as a result of universal immunization programs. As of 2008, approximately 77 countries had incorporated hepatitis B vaccinations in their national infant immunization campaigns.[26] For instance, in Taiwan, the presence of chronic infection in children declined by 90 percent as a result of the vaccination program.[28] The hepatitis B vaccine was first licensed for use in the United States in 1981 and is part of routine vaccination programs for infants and children worldwide.[28] A comprehensive strategy to eliminate hepatitis B virus transmission was

implemented in 1991 in which vaccines were routinely recommended.[29] It has been effective in reducing the incidence of infection which has attributed to the massive declines in the spread of HBV infection. In 2004, the incidence of acute hepatitis B was 2.1 per 100,000 population representing a 75 percent decline since 1990.[28]

Disease Prognosis The outcome of hepatitis B infection includes asymptomatic infection, acute hepatitis B, chronic hepatitis B, cirrhosis and hepatocellular carcinoma, also known as liver cancer. Acute infections occur in approximately 1percent of perinatal infections, 10 percent of early childhood infections, and 30 percent of late infections (persons more than 5 years old). Of those with acute hepatitis, fulminant hepatitis occurs in 0.1 to 0.6 percent. The occurrence of chronic hepatitis is 80 to 90 percent of people infected perinatally, 30% for children infected before the age of 6 and less than 5% for otherwise healthy adults.[26]

Research suggests that comorbidities such as concurrent HIV infection may have an important role in the development of morbidity associated with hepatitis B. Roughly 10 percent of the 40 million people infected with HIV are coinfected with HBV and the presence of HIV markedly increases the risk of developing HBV-associated liver cirrhosis and hepatocellular carcniomas. [26]

Symptoms and Treatment Hepatitis B virus can cause an acute illness with symptoms that last several weeks, including yellowing of the skin and eyes (jaundice), dark urine, extreme fatigue, nausea, vomiting and abdominal pain.[27] Infected individuals may also be asymptomatic, making it necessary to use diagnostic tests to identify infection.

There is no specific treatment for acute hepatitis B as care is aimed at maintaining comfort and adequate nutritional balance, including replacement of fluids that are lost from vomiting and diarrhea.[27] However, there are at least seven medicines approved for treating

chronic HBV infection that have been shown to delay progression of cirrhosis, reduce the incidence of HCC and improve long-term survival.[29] They include inferferon and antivirals including adefovir dipivoxil (hepsera), Entecavir (Baraclude), and Lamuvidine (epivir-HBV, Zeffix, or Heptodin). Despite the benefits of multiple treatment options, these medicines are not readily accessible in resource-scarce settings.[26]

2.5 Refugees and Their Health Needs

The United Nations High Commissioner for Refugees defines a refugee as anyone who: "…owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country."[30]

From 2000 to 2009, at least 600,000 refugees from more than 60 different countries have been resettled in the United States, and it is now home to more than 300,000 refugees from around the world.[32, 33]

Many refugees hail from nations with areas with high endemicities of malaria, HIV, tuberculosis and hepatitis. Refugees may have higher mortality in camps than in their home country as a result of continued interethnic strife, sexual violence, and disease epidemics than in their home country.[34] Prevailing conditions in refugee situations result in a greater risk of infection.[35]

Hepatitis B is endemic in Africa and South East Asia and death due to cirrhosis or hepatoma occurs in up to one third of carriers who acquired hepatitis B perinatally. Individuals who have had a blood transfusion, ritual female circumcision or surgical procedure, or are

African or South East Asian refugees are considered at risk for hepatitis C.[34] Among Vietnamese-American adults chronic hepatitis B infection rates range from 7 to 14%. Carriers of HBV are much more likely to develop liver cancer than non-carriers, with Vietnamese males having the highest liver cancer incidence rate of any ethnic group in the United States (41.8 per 100,000).[37]

2.6 Providers' Challenges

Inadequate physician training on the unique challenges faced by refugees contributes to worsening of their medical issues.[34] Language barriers, cross-cultural medicine issues, and low levels of health literacy provide significant challenges to caring for this population.[36]

One of the major unmet needs in the refugee population is the need for interpretive services.[38] The lack of translators, particularly for new or small groups of refugees, is a significant barrier to health care.[34]

Logistical issues such as a lack of transportation and inability to schedule appointments with specialists further contributes to poor compliance. A lack of familiarity with and understanding of insurance also contributes to poor outcomes. This can be seen in the lapse of insurance coverage because of a missed reapplication deadline.[36]

Stigma is also a factor that plays a role in the health care needs of refugees. For instance, in studies examining the prevalence of hepatitis B in Asian communities, stigma is shown to have a significant negative association with screening behavior. Those who feared being socially isolated were unlikely to get screened. Efforts to reduce stigma would benefit this community along with enhancing awareness and knowledge about HBV infection and its consequences.[39]

2.7 Coalitions for Refugee Health

There is limited guidance on the evaluation of the process of coalition formation to address refugee health, hence the motivation for this project. However, coalitions have been utilized successfully for the promotion of health needs of refugees. For example, in a community based participatory research study conducted by the African Partnership for Health Coalition in Oregon, researchers were able to identify and prioritize the needs of the African community. Findings of this study identified attitudes of the stressfulness of life in America, the challenges of gaining access to health care, and the pervasive feelings of disrespect and lack of understanding of Africans' health needs.[40] Coalitions such as this have proven to be useful as vehicles for health promotion for refugees.

CHAPTER III
METHODS AND PROCEDURES

3.1 Study Design and Data Collection

A mixed methodological approach was used combining participant observations and semi-structured interviews to assess the formation of the coalition. Observation of quarterly meetings occurred from August 2013 to April 2014. Semi-structured interviews of coalition members were conducted from April 25 to April 28, 2014. Open-ended questions were asked to allow participants to explain and qualify their responses, give multiple answers, and provide responses not anticipated by the researcher.

3.2 Participant Observations

The primary investigator examined the process of the formation of the coalition attending and participating in meetings held on August 21, 2013, November 6, 2013, January 22, 2014, and March 13, 2014. Observations were made of the organizations represented, the structure, the level of engagement, topics presented, and types of questions asked. Detailed field notes were taken that included participant dialog and interactions among participants. Information was collected from each meeting, including agendas, PowerPoint presentations, and other handouts. The researcher also assisted with tasks such as room set up and bringing in speakers.

3.3 Interview Instrument and Process

The interview questions were designed to understand the viewpoints of the participants and allow them to share their feelings about the progress of the coalition thus far. An interview tool titled “Refugee Viral Hepatitis Coalition Interview Questions” (Appendix A) was developed for use during semi-structured interviews. It contains ten questions and an opportunity for interviewees to offer additional comments if interested. Questions were designed to learn about

the attitudes members held about the progress of the coalition, their purpose for being a part of the coalition, their ideas for improvement of the coalition, and general attitudes about the utility of the coalition.

Selection of participants for interviews was based on responses to e-mails, phone calls or a visit to their work place requesting their participation. Contact information was obtained from the coalition coordinator. Prior to the mass e-mail, the coalition coordinator informed the researcher that e-mail communication regarding feedback about the coalition has presented a challenge in the past. Therefore, the researcher proceeded to make phone calls and work place visits shortly after sending out the e-mail request. A total of 141 e-mails had been sent out requesting participation in interviews. Of those 141 members contacted via e-mail, 39 members were contacted by phone and five were visited in their place of work and asked to participate in the interview. Some of the phone numbers and e-mail addresses on the contact list were faulty and made it difficult to get in contact with some members.

At the start of the interview, interviewees were told that their feedback would be used for the improvement of the coalition. They were also informed that none of the answers they provided would be linked directly to them. Questions were asked in a sequential manner from question one through question ten with an opportunity to share additional comments at the end.

3.4 Interview Questions

Below are the questions posed in the semi-structured interviews:

1. Why is there a need for a coalition?
2. How was the coalition formed?
3. What is your role in the coalition?
4. What are the major obstacles in building the coalition?
5. What are the next steps in the building of the coalition?
6. How has the coalition fared in meeting its goals?
7. How do you think the coalition building process can be improved?
8. What do you hope to gain from being a member of the coalition?
9. What resources are needed to help realize the goals of the coalition?
10. What other measures can coalition members take to ensure its success?

3.5 Data Analysis

The participant observation data was examined for trends and common themes observed from meeting to meeting. Documents that were collected and generated during the process were reviewed. These included emails, memos, meeting agendas and minutes, reports, strategic planning documents. Interview data was examined for common themes that recurred throughout out the responses given.

CHAPTER IV
RESULTS

4.1 Participant Observation

Since its inception in 2013 the Viral Hepatitis Coalition has held quarterly meetings from August 21, 2013, to March 13, 2014. Below is a discussion of the participants present at the meetings, some of the major topics on the agenda and a description of how the meetings progressed.

The Refugee Viral Hepatitis Coalition took the initial step of bringing together individuals from a broad spectrum of backgrounds. They include lead clinicians, case workers, health administrators, and community leaders from the various refugee populations. Membership contains individuals from a number of the entities that play a role in addressing the health needs of the refugee population. At each meeting, there was consistent representation from both local and state government, academic institutions, refugee agencies, volunteer agencies and community organizations. Many of them were recruited by the coordinator of the coalition. Some worked directly with the coordinator in meeting the needs of the refugee population, some members knew each other based on previous encounters and some were invited to the coalition through a contact with other participants.

There were representatives from local resettlement agencies which are the first organizations that work with refugees once they enter the state.[31] They provide most of the needed services including food, shelter, clothing and transportation. At these organizations, refugees have assigned case management workers who help them get to the Board of Health for screening, assist with obtaining treatment for any conditions they may have along with ensuring that their vaccinations are consistent with state requirements. Some of the resettlement agencies

include World Relief, the International Rescue Committee, Catholic Charities and Refugee Resettlement and Immigration Services of Atlanta. These organizations tend to work with refugees for up to three months. Refugees are then assigned to bridge agencies. In Georgia, Refugee Family Services and Refugee Women's Network are two of the bridge agencies. They provide services pertaining to English as a Second Language (ESL) needs, immigration documentation and assistance with job readiness training. These organizations tend to work with refugees for up to five years.

In the initial meeting on August 21, 2013, there was a discussion of the need for the coalition and the challenges of treating hepatitis in the local refugee population. Topics on the agenda included the screening and vaccination program at the local board of health and the recent push to additionally screen clients for hepatitis C. The local board of health screens the majority of refugees upon entrance into the county for a number of health conditions. In addition to tests for hepatitis B, tests for anemia, blood lead level, dental issues, malnutrition, diabetes, mental health issues, disability-related issues, hearing loss, vision problems, pregnancy, sexually transmitted diseases, and tuberculosis are conducted. At this organization new arrivals receive necessary immunizations and are directed to appropriate community agencies and medical providers to further meet their needs.

At the initial meeting there also was a discussion of the purpose of the coalition, the essential elements of reducing the burden of hepatitis, and the challenges with linkage to care. These elements are (1) the screening and vaccination program, (2) support to link refugees to care (support and treatment program), and (3) education. All three components are performed by the

and a number of other local community providers. The involvement of a number of different entities working to respond to the hepatitis burden makes it challenging to determine how best to go about raising funds for educational campaigns and medications to those who lack insurance. Other questions raised were: How do you design a campaign to make sure that everyone is immunized? How do you set up social service and support for individuals? Once they are identified they must be linked to care and this is not easy if individuals are not working and don't have insurance.

The quarterly coalition meetings consistently had speakers who discussed topics that were relevant to the group. Each meeting also had a member discuss the Affordable Care Act and the impact it was likely to have on the refugee population. The benefits and protections in the Affordable Care Act are particularly important for refugees, as they often arrive to the U.S. after years without access to adequate medical care. It will grant refugees access to affordable health coverage and protection against insurance practices that can deny coverage to individuals with pre-existing conditions. It is extremely important to understand the impact as it bears directly upon the response to patients living with hepatitis B.

When the coalition initially convened, one of the major objectives was to ensure that a vision statement was agreed upon. In order to achieve this, at the second meeting, members in attendance were divided in groups where they were asked to work together in brainstorming ideas for this statement. At the end of the session, work groups shared their proposals with the larger group and votes were taken to select the statement that best reflected the vision of the coalition. A final decision was made in a subsequent meeting, giving the organization its focus. It was important to come up with a vision statement early on to give direction to the coalition. Any successful coalition has a central focus. Moreover, working with a group of individuals with

differing belief systems and political interests could lead to conflict if not addressed early on. Developing a vision statement helped to keep the group focused on hepatitis B screening, treatment and education efforts and less on areas of conflict.

The process of deciding on a vision statement was not an easy task. The process began at the meeting on November 6, 2013, and continued through the meeting on January 22, 2014. After the November meeting, an e-mail was sent out by the coordinator asking participants to vote on one of three vision statements that were decided on during the meeting. Feedback was minimal and responses were insufficient in order to make a decision about the vision statement. Thus, the meeting on January 22, 2014, provided an opportunity for members to revise and refine the vision. Before leaving, members were asked to vote on a statement and shortly after it was finalized.

Below is the final vision statement:

"To serve and empower Refugees affected by viral hepatitis B and hepatitis C, enhance quality of life, and create lasting solutions to healthcare issues through advocacy, education, and affordable services."

Starting a hepatitis support group in the community was also a topic addressed at one meeting. A representative from the America Liver Foundation discussed the benefits of and steps in developing a hepatitis support group. There was a discussion of the stigma attached to having hepatitis and the need for people to come together and talk about their feelings with others. Support groups are also a way for individuals to share information about their treatment they use and how they are responding to it. As members currently living with hepatitis B benefit from talking with others about living with their condition, this topic was very useful for the direction of the coalition.

At the meeting on March 13, 2014, members of the coalition offered to host future coalition meetings. Meetings thus far had been hosted solely by the local board of health, but research on successful coalitions states that involvement of members leads to better outcomes than just one organization performing the majority of the work.

4.2 Interview Data

Interviews were successfully conducted of 17 individuals within a four-day period. Nine of them were interviewed in person and eight were interviewed over the telephone. From the 17 interviews, the answers were tabulated and examined to find the commonalities and differences present between them. Key points that participants thought were important to the success of the coalition were also noted.

After examining all the answers, four themes were evident among the responses provided by the interviewees. These were:

(1) Improve awareness and treatment of hepatitis B

(2) Increase formalization of the coalition to promote growth

(3) Increase civic engagement

(4) Coalition Strengths

The questions and their responses were then grouped together with themes that best reflected the essence of the ideas presented. The answers to questions 1 and 2 best fit theme (1) ; 3, 4, 5, & 7 best fit theme (2); 8, 9 & 10 best fit theme (3) and theme (4) was expressed by the responses to question number 6.

Theme 1: Improve awareness and treatment of hepatitis B

Question 1: Why is there a need for a coalition?

Question 2: How was the coalition formed?

The answers to these two questions presented information about the coalition's history and the need for the coalition. Improved awareness and treatment would alleviate the burden of hepatitis in the community. Of the 17 interviewees, there were four categories of answers that were presented for the need for a coalition. One was bridging gaps to care to ensure that clients are receive follow-up during their treatment. Another was the need to increase collaborations and partnerships with other agencies and organizations that work with the affected population. Third was improving supportive measures to ensure that the patients actually were receiving treatment from the community providers or agencies they were referred to. The fourth category was the need to improve funding to respond to the needs of the hepatitis burden among the refugee population, as translation resources were needed to better ensure that surveillance measures were being implemented.

"There is a need to be able to educate stakeholders on the importance of understanding viral hepatitis and the population involved. The need for testing and availability of vaccinations are also important."

Regarding the formation of the coalition, 13 respondents mentioned that they were not sure of the details of the formation of the coalition. Three indicated it was derived from a grant for screening and to develop capacity building from the collaboration of the Community Wide Services division and the Health Assessment and Promotion programs at the board of heatlh.

Theme 2: Increase formalization of the coalition to promote growth

Question 3: What is your role in the coalition?

Question 4: What are the major obstacles in building the coalition?

Question 5: What are the next steps in the building of the coalition?

Question 7: How do you think the coalition building process can be improved?

The answers to these questions suggested that building the coalition was necessary for achieving its ultimate goals. A significant part of this could be achieved through increased organization and formalization of the coalition.

When asked about their role, ten of the 17 respondents identified themselves as participants or members of the coalition. Of the two who self-identified as speakers, one also identified their role as being a resource for knowledge about hepatitis. The remaining five respondents simply identified their role as representing their organization.

The most popular responses regarding the major obstacles in building the coalition were "time" and "commitment." Time was the #1 response among respondents, with nine members citing it as an obstacle. It was a challenge because many people have busy schedules and other responsibilities outside of their work with the coalition. A lack of commitment was also cited as an issue. Members stated that there was a lack of consistency from one meeting to another as some individuals would attend one or two meetings and miss others. Some people may not have felt connected to the issue if they have not had personal experience with hepatitis or believed that it affects them directly.

"One common obstacle is that not everyone who attends the first meeting is able to attend the second or third meeting. Therefore, consistency or committed attendance is usually an obstacle in the formation of any group."

The challenge of getting people "on the same page" was cited by two respondents. When individuals come together from a number of different educational and awareness backgrounds, it may be a challenge to get them to agree on the focus of the collaboration. Some may be more aware of the issues than others and it may pose a challenge to maintain the interest at the different meetings. In order to foster more awareness among members participants are encouraged to share information with each other before and after sessions.

A lack of funding was cited by two respondents because there was a need for materials to promote the vision of the coalition. Brochures are needed in different languages and equipment may be needed for meetings.

"A major obstacle is money. There must be a place to meet, ways of getting info out to people, food, sometimes speakers want money, conferences, meetings, info sessions so that people know about it, help to get the word out."

Regarding the next steps in the building of the coalition, the majority of respondents mentioned the need for the development of a more formalized structure, six suggested increased opportunities to participate in the coalition, and two said there was a need to publicize the coalition and recruit more members.

Of the answers on how the coalition building process can be improved, five said there was a need for increased structure and six reported that membership was the key to improvement. One suggested that there was a need for increased flexibility of meetings to improve participation such as a variation of times and rotation of locations. This could also

include use of teleconferencing or videoconferencing such as Skype in order to allow people who are not able to be physically present to still join in remotely. There is the need for committed people who will see to it that tasks are completed. There is also a need for the word to get out in the community that the coalition exists so that people will participate and get involved.

Three respondents addressed issues relating to the nature of the meeting. There was dissatisfaction with the many topics that were presented during the meetings. Having a packed agenda made it difficult to learn about any one particular topic in a meaningful way and sometimes it felt overwhelming. Information shared at the meeting was also requested electronically in order to revisit ideas presented and gain clarification about topics that were not discussed at length.

Theme 3: Increase civic engagement

Question 8: What do you hope to gain from being a member of the coalition?

Question 9: What resources are needed to help realize the goals of the coalition?

Question 10: What other measures can coalition members take to ensure its success?

Answers to the question of what participants hoped to gain fell in four general categories: reducing the burden of disease, increasing knowledge about the issues, increasing collaboration and communication among community organizations and increasing awareness about how to develop community support for a project. The most common response was to improve their own knowledge base about the health challenges in the refugee community. The majority of respondents wanted to learn more about the problem of hepatitis and about the services offered

to respond to those with the condition. Five respondents mentioned that they wanted to increase awareness of the issue through educating the community and increasing the amount of screening.

The responses regarding needed resources fell into three broad categories: funding, human resources and information sharing. The majority of respondents (10) mentioned that money would be helpful. Six respondents stated that adding to the membership would be beneficial. The need for a dedicated staff member was cited by two respondents. The recruitment of hepatitis patients to serve on the coalition was mentioned by another respondent. The need for interpreters to assist with patient follow-up was mentioned as one way to ensure that clients were receiving treatment after screening.

The need for informational awareness was mentioned by two respondents. One mentioned that there was a need for educational materials in different languages that could be used by providers as well as members in the community. It is important to increase awareness among providers as they too are unaware of the impact of hepatitis in this population.

"Creating awareness among providers is important. People get let go from their jobs because they have hep B. Many providers are not familiar with hep B in the refugee community and when people go for treatment, they may not get screened for it even though they are in a high risk population."

To the question of the other measures that can be taken to ensure the success of the coalition, the most popular answer was to increase participation, suggested by four respondents. However, the answers to this question varied widely. Below is the list of responses:

- Find out about available resources for people.
- Recognizing one's limits to reduce committing to tasks that cannot be completed.
- Have more meetings, maybe one every other month as opposed to quarterly.

- Commit to roles.
- Be prepared to share updates during each meeting.
- More participation among members.
- Make sure people are sticking to goals.
- Publicize the coalition.
- Possibly paying people to do the work of the coalition.
- Advocate for mandatory screening of Hepatitis B of people arriving from countries where it is endemic.
- Recognize the people who want to be there and weed out the rest.
- Follow-up with patients.

Theme 4: Coalition Strengths

Question 6: How has the coalition fared in meeting its goals?

When asked how the coalition has fared in meeting its goals, the majority of respondents stated that it was good, five stated that it was hard to tell, two stated that it was great. One member stated that it was a very positive thing that there were representatives from government as well as community organizations that work directly with the refugee population. One of the benefits of bringing together these members is to pool resources. A number of organizations and individuals together may have the resources to accomplish a task that none of them could have done singly, and so far this organization has involved a number of different entities.

4.3 Interviewees' Additional Comments

When asked about additional comments, seven responses were given. Four respondents believed that awareness of hepatitis was important and that education was essential to reducing transmission. Two respondents mentioned that recruiting efforts needed to be improved to include those who will be an asset to the coalition. One respondent suggested that incentives were needed to get the refugee community to understand why screening for hepatitis matters to them. Another respondent suggested that the local board of health may be able to expand services to include treatment since refugees are already familiar with the organization and it has many of the resources to provide services.

CHAPTER V
DISCUSSION & RECOMMENDATIONS

5.1 Discussion

This research sought to evaluate the formation of the Refugee Viral Hepatitis Coalition of Georgia. The participant observations and interviews offered many insights to the feelings and beliefs held about the coalition. Much can be acquired about the measures that can be taken to strengthen the community collaboration and increase participation among members.

Results from both observations and interviews indicated that the coalition has remained focused to its original goal of capacity building in order to reduce the hepatitis burden in the refugee population. The majority of its members were interested in increasing their knowledge of hepatitis and learning about services that are available for those who need it. Members were committed to learning about the challenges of treating hepatitis, concerned about ways to increase awareness, and ready to share their knowledge and resources in a meaningful way to advance the cause. This is consistent with the original intent of the coalition.

Additionally, the inclusion of members representing entities that play a role in responding to the needs of the refugee community is a major strength of the coalition. Each meeting has included individuals from government, non-profit organizations and the refugee communities in Georgia. There has been representation from refugee resettlement agencies, bridge agencies and community health organizations.

One noteworthy occurrence is the expansion of scope beyond hepatitis B to also include hepatitis C patients. This development occurred after the coalition's initial two meetings in 2013. This was a result of policy changes that allows for screening for hepatitis C. This expanded focus of the coalition is characteristic of the dynamic nature of community-based

coalitions as they are constantly being shaped by new policies, membership and needs of the population being served.

One of the major challenges of the coalition thus far is obtaining funds to support awareness and educational campaigns. In order to reach members of the refugee communities, materials that are culturally appropriate are needed. Individuals who are equipped to reach the various target communities are also needed to develop and maintain relationships with community members. The next steps will be to continue collaborating in order to implement the goals of increasing awareness, screening and treatment. For example, in May (Hepatitis Awareness Month), coalition members planned to collaborate to raise awareness at a local community center that serves a large refugee population. The coalition will also work to increase screening and treatment efforts in the community.

5.2 Study Limitation

One of the areas of potential bias in the research can be attributed to sample selection since individuals who agreed to participate in the interviews may have been more interested in the progress of the coalition. This could be problematic as individuals willing to offer their insights may not represent the entire coalition membership. Also, some who chose to participate in the study may have been more knowledgeable of the coalition development which may have led to self-selection bias.

5.3 Recommendations for the Coalition

Based on the observations and interviews, the researcher has arrived at several recommendations for the coalition. One of the recommendations is to recruit more members from the refugee communities most affected by hepatitis. Having greater representation of those

that comprise the target population or who are closer to the target population will be helpful in reaching that population. This may also increase buy-in from the community.

As a coalition currently in its formative stage, one of the next steps should be to assign roles and responsibilities through creating committees. Structure will help to define roles and responsibilities in the coalition so that individuals can recognize their responsibilities and play an active part in the progress of the coalition.

There is a need to significantly improve recruiting efforts to increase the likelihood that new members will be invited and become a part of the membership. It would also beneficial to have individuals who are currently living with hepatitis or are close to individuals with hepatitis to be a part of the coalition. These individuals may be able to offer insights that others may not be aware of.

One of the major goals of the coalition is to increase awareness of hepatitis among the local refugee population in high risk categories, as well as among health care providers who may not be familiar with at-risk groups. When health providers are not aware of the prevalence, they miss opportunities to intervene early. Awareness among providers can be achieved through the dissemination of educational materials to medical facilities as well as trainings that offer continuing education credits (CEUs). In order to increase awareness in the broader community, educational materials can be shared at health fairs, and community centers where refugees are likely to frequent. Public service announcements can be made on local television networks and radio stations that serve the refugee population.

Funding is necessary to improve recruiting efforts, develop educational materials and hire staff to help with the major tasks of the coalition. Obtaining a staff member or an academic

intern who is able to commit time and energy to making sure essential tasks are completed in a timely manner will greatly help move the coalition forward.

5.4 Conclusion

Results indicate that the coalition building efforts have been proceeding in an overall positive trajectory. Responding to the hepatitis B needs of local refugees presents many challenges that participating members are working together to address. Some major differences in addressing the issues were reconciled through participants coming together and deciding on a common vision statement. Observations and interview results indicated that members of the coalition play a vital role in the development of the coalition and influence the direction it follows. Members are interested in improving the coalition through increased formalization and recruitment to ensure that objectives are being met.

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