Addressing the Educational and Interventional Needs of Wiskott Aldrich Syndrome (WAS) Patients and Families

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Addressing the Educational and Interventional Needs of Wiskott Aldrich Syndrome (WAS) Patients and Families

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MPH 683: Integrated Learning Experience (ILEX)

Dr. Zahra Goliae

August 16, 2022
Abstract

Wiskott Aldrich Syndrome (WAS) is an immune system (immunodeficiency) and blood disorder that increases the risk of severe infections and bleeding. A patient with WAS has a significant reduction in the size and number of platelets (micro thrombocytopenia), meaning there is a reduced ability to form blood clots and stop bleeding. WAS affects approximately 1 in 250,000 males in the United States. Public information on WAS is predominantly scientifically based, which makes it difficult for families to fully understand the syndrome, the impacts of severe bleedings on patients’ daily activity, and how to improve the patients’ quality of life. This study examined the existing resources available for patients and families and created recommendations and new resources based on the most identified needs. The Wiskott Aldrich Foundation is dedicated to ensuring that individuals are made aware of the syndrome and are prepared for any emergency situations (Ex. Severe bleeds). This study identified a lack of a clear and concise information guide on the syndrome and how to prevent the bleeding to educate school staff and teachers who spend the most hours of days with these kids at school. Based on the findings, this study introduced new resources that can be used to further educate the general public on WAS and ensure that a patient’s health and safety are best attended to. The public health impact that providing clear and concise informational guidelines entail include a peace of mind for parents that are weary of leaving their child in another person’s care as well as trained and informed individuals readily available to attend to a wiskott patient’s needs. Future needed research should consist of studies on how informed teachers feel they are when needing to address an emergency situation, studies on how prepared schools are for emergency bleeds (Ex. Are kits packed in every classroom setting, or studies on what suggestions Wiskott families have to better care for their patient as well as whether these suggestions have been implemented in any way.
Introduction

Wiskott Aldrich Syndrome (WAS) is a rare, genetically inherited immunodeficiency disease that affects the function of the white blood cells of a patient (Massaad et al., 2013). This can result in a patient being more susceptible to serious cuts, bleeds, and infections. The most common ages for this syndrome’s symptoms are between birth to 23 months. Approximately 1 in 250,000 males are affected by WAS in the United States (Perry et al., 1980). The life expectancy of a treated wiskott patient is around 20 years while that of a non-treated patient is 3.5 years. Patients that undergo a bone marrow transplant have shown survival rates greater than 95%.

Patients with WAS are prone to abnormal bleeding which can pose a risk when outside of immediate medical care, such as at a school setting. Given that the syndrome is rare, families and patients may struggle to find resources to best address their concerns. This may also be the case in the educational setting as teachers and students are limited to treating the symptoms associated with the syndrome due to the lack of resources readily available.

This study aims to review what literature articles currently report on WAS, and to recommend further resources that can positively impact a Wiskott patients’ health and safety based on the lack of attention, education, and information that is not readily available today. The goal is to keep a WAS patient’s health at top priority by ensuring those around the patient are provided necessary steps to address syndrome-related complications. The outcome of this study will help with raising awareness on WAS and encouraging more understanding of what the syndrome is. The understanding will stem from peers of Wiskott patients being informed on what a Wiskott child’s needs entail of and ensuring that such needs are being met. Future possible research intervention or policy can consist of direct care being present for wiskott
patients in the school/classroom setting as well as mandatory training for Wiskott peers on how to manage emergency bleeds.

Background

WAS is caused by a mutation of the Wiskott-Aldrich Syndrome protein (WASP) that is thought to have a role in actin cytoskeleton organization and cell signaling (Jin et al., 2004). Mutations happen when there is an alteration of the sequence of the base codes for the formation of amino acids in proteins. WASP is found mainly in a patient’s white blood cells and platelets. Given that it has an active role in the actin cytoskeleton of the cell, its absence can lead to a disruption in the cell’s signaling and lead to early cell death. This can contribute to the patient developing an immunodeficiency (Wiskott Aldrich Foundation). Other risk factors associated with WAS include eczema and rheumatoid arthritis. Given that the syndrome is rare among females, the population at risk of WAS is predominantly new-born males. The severity of the syndrome has been measured on a broad range based on the mutation in the WAS gene (Massaad, 2013). Researchers have used a scoring system on a scale of one to five to differentiate the WAS gene’s many mutations. There are more than 300 unique mutations, with the most frequent being in the following order: missense mutations, splice-site, deletions, nonsense, insertions, and complex. WASP promotes white blood cells to change shape and move throughout the body. However, patients with WAS have an absent regulation of their white blood cells which limits the ability to decipher between one’s own cells from foreign cells. Foreign cells may include pathogens, bacteria, viruses, or deformed cells. When the body is not able to decipher the two, it may signal lymphocytes to attack a patient’s healthy cells and result in autoimmunity (Wiskott Aldrich Foundation). WAS is believed to result in a significant reduction in the size and number of platelets known as micro thrombocytopenia (Baldini et al, 1972). Similar to other syndromes,
Wiskott has a wide variation in severity. Its classic form is labeled Wiskott Aldrich Syndrome (WAS) and is mainly used to generalize the syndrome. X-Linked Thrombocytopenia (XLT) is the milder form of WAS and affects the platelets with little or no immunodeficiency. (Zhu et al., 1997).

Given that a WAS patient is more prone to bleeds, it is important to take the necessary steps of ensuring the bleeds are being properly managed. Symptoms related to WAS can be treated by medications, therapy, and bone marrow transplants. To properly treat a WAS patient, it is important to determine the type of therapy that is most effective (Rivers et al., 2019). Such therapies include stem cell gene therapy or hematopoietic stem cell transplantation. Stem cell gene therapy is an innovative therapeutic strategy for immunodeficiency disorders (Boztug et al., 2010). WAS falls into this category since the syndrome is associated with autoimmunity. Stem cell transplantation takes multipotent hematopoietic stem cells and transplants them to replicate inside of a patient and produce healthy, normal blood cells. This method has been successful among Wiskott patients that have low blood cell counts due to frequent bleeds (Burroughs et al., 2020).

**Importance of Prevention of Bleeds**

A Wiskott patient’s platelet count can vary from below 10,000/ cu.mm to 70,000/cu.mm. The count can be influenced by infection or common un-traceable patterns (Wiskott Aldrich Foundation). The greatest prevention of bleeds is from avoiding serious injuries. Injuries such as head trauma and bruising can be commonly noted among Wiskott patients and can be life threatening. To prevent bleeds, individuals should be made aware of its commonality and use precaution to avoid known causes of bleeds. Signs of internal bleeding include headaches, vomiting, dizziness, double vision, seizures, and stiffness (Wiskott Aldrich Foundation). To
prevent bleeds, families are recommended to safety proof their house by covering sharp corners and securing any wall art/ items. Given the severity of WAS, individuals are not encouraged to engage in contact sports that are known to result in direct hits. Once diagnosed with WAS, the individual’s clinical score is derived from pre-set standards that include the presence of WAS related complications. Overtime, an individual’s score on the scale may increase depending on their signs and symptoms. Those with a high WAS scoring, often categorized as a score of 5, at a young age are categorized in a group believed to be highly at risk of morbidity and mortality (Buchbinder et al., 2014). The reasons being that characteristics and outcomes of early-onset forms of WAS have also been associated with autoimmune disorders, thrombocytopenia, and some forms of cancer (Mahlaoui et al., 2013). A subset of 160 infants were identified to be significantly more likely to have a high WAS scoring before the age of 2. Thirteen of these infants developed severe refractory thrombocytopenia, 15 developed autoimmune hemolytic anemia, and 4 died before receiving allogeneic hematopoietic stem cell transplantation (HSCT) (Mahlaoui et al., 2013). The study found it is life-dependent for infants that do score high within WAS-related clinical parameters to have HSCT as early in life as possible to prevent further complications and mortality. The burden that families face can be from the severe, life-threatening presentations of WAS in their young children. In a 2003 article, the records of 55 patients with WAS were reviewed to determine the risk factors and outcomes of syndrome-like complications. 72% of the cohort developed at least one autoimmune or inflammatory sign (Dupuis-Girod et al., 2003). Developing an autoimmune or inflammatory complication can result in life-long issues and place the child at higher risk of infections or other health complications. When researching WAS, an individual will find extensive publishing on the scientific background of the syndrome but will struggle to find resources for day-to-day
concerns. Important resources can include guidelines on how to respond to an emergency bleed and well as general information on WAS. Having these resources will ensure that a Wiskott patients’ peers are prepared when an unexpected bleed does occur.

**Lack of basic understanding of WAS for the average person**

Much of the information above is only understandable for someone with a scientific background. This is not the case for many of the family members that have a Wiskott child and are unsure how to comprehend scientific findings. Their inability to decipher the information can add to their overall concern of their child’s well-being. This is a problem in terms of families feeling helpless in wanting to help their child in need but not being aware of how to do so. As a public health expert, I find it is my obligation to summarize scientific literature and make it easily comprehensible for the average person today. More families, schools, and communities can have children with WAS and not know how to manage a bleed in an emergency situation.

**Social Ecological Theory**

The Social Ecological Model is composed of four sections: Individual, Relationship, Community, and Societal. It considers the complexity of each of these factors and how they interplay with society and health. Given the vast range of categorized factors, these four general sections serve as a useful framework to decipher between the many influences that affect society and health. This same model can be applied towards this paper since WAS can result in a patient being heavily influenced by their personal relationship, that being parents, teachers, friends, etc., as well as their environmental relationship, that being safety, an emergency response plan, etc. The Individual consists of knowledge, attitudes, and beliefs. The relationship/interpersonal consists of influence friends, families, and colleagues. The community consists of the relationships with organizations. The societal consists of public policy and laws. In regard to this
topic, “the individual” applies most since the purpose of this paper is to educate and enhance the attitudes towards WAS. That is, the individual should be provided the knowledge, understanding, and resources to then educate others. This has been shown throughout several scientific articles, as researchers have been able to use advanced tools to diagnose and treat WAS more effectively (Buchbinder et al., 2014). Educating others can begin with a conversation on the effectiveness of treatments today. As stated before, there are many therapies used to treat WAS. Wiskott families, friends, and peers can become more aware of the success stories of such treatments and advocate for their peers to receive the same treatment. This may require the individual to seek information outside of their circle of peers, which leads many to wonder where to turn to.

It is of most importance to avoid any deaths from syndrome-related complications, such as excessive bleeding. Wiskott Aldrich Syndrome affects individuals worldwide, so the methods used throughout this research proposal and throughout the internship with Wiskott Aldrich Foundation can be shared globally.

Methods

To ensure that the public is well-informed on WAS, this study aims to create supporting resources and educational materials that summarize WAS information in a clear and concise manner. This project includes two steps: a literature review and my internship with the Wiskott Aldrich Foundation.

The first step is to become aware of what information is readily available for Wiskott families and patients today. This will be done by examining the existing literature and materials available on the web using the following search terms: “Wiskott Aldrich Syndrome”, “Wiskott Aldrich”, “Gene Therapy”, “Thrombocytopenia”, and “Low platelet count”. 
Other websites that were accessed include the Immune Deficiency Foundation’s site and Wiskott Aldrich Foundation’s site. The existing resources will be categorized by their information. These categories include scientific literature, organizations, educational attainment, treatment opportunities, and government involvement.

The second step of this project is my internship with the Wiskott Aldrich Foundation. The objective was to fill in the gaps in missing information for Wiskott families and patients. These gaps may include summarized information for parents, teachers, and staff to have readily available when needing to inform someone on Wiskott, emergency bleeding kits for an emergency situation, or a clear understanding on WAS and the affects it can have on a patient. I will do this by conducting the research on WAS to provide the background information on the syndrome. This includes a clear and concise definition, who is affected by WAS, and how they are affected. I will also communicate with Wiskott families via the private Wiskott Aldrich Foundation Facebook group to ask what resources would be most useful to them.

The Wiskott Aldrich Foundation is a volunteer run, non-profit organization, that is dedicated to funding research on improving WAS. These funding resources can result in a Wiskott family being able to receive life-saving gene therapy or blood transfusions. The foundation also ensures families with a Wiskott child have a support group via social media and group meetings to discuss common questions and concerns they face when dealing with WAS. The foundation’s vision and mission are to serve patients with WAS and their families by providing educational, financial, and emotional support as needed. The foundation has also set goals to continue staying informed on the most current news, research, and findings regarding WAS so that its members are aware of any developments in treatment or care for patients.

**Recommendation, Results, and Public Health Impact**
More efforts to educate the public of WAS, can result in a more effective response to the syndrome in real-time. The existing resources at the foundation, national, and international level are limited to scientific articles that describe the genetic mutations that cause WAS. There is nothing available to train or provide resources for school staff and teachers who have students under their care for extensive periods of time in the school setting. This lack in basic resources for teachers and staff can place a child at risk of further complications if their syndrome-like complications are not being quickly addressed. These complications may include dizziness, bleeding, or frequent injuries. Which is why efforts seen by organizations like the Wiskott Aldrich Foundation are essential so that families and Wiskott peers are provided the necessary information on managing the syndrome and providing the emotional support to the patients that may be frustrated with the complications. The Immune Deficiency Foundation is another organization whose mission is to improve the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency. The Foundation works to provide education and research while being empowered by advocacy. This Foundation would fit under the community aspect of the social ecological theory since it promotes fostering a community with better resources to address any immune deficiency related issues. Orchard Therapeutics is a biotech company working to end genetic and severe diseases. In 2019, the company received Regenerative Medicine Advanced Therapy (RMAT) Designations from the Food and Drug Administration (FDA) for treatment of Wiskott Aldrich Syndrome. This existing resource will be used on an international level since the results shown from one treatment trial will determine whether this course of treatment is safe and effective. Once determined to be safe and effective, other countries can begin their own process of having RMAT approved in their respective locations. A
few efforts will be discussed below to highlight how Wiskott patients could be further supported with their own syndrome-related complications.

**Emergency Bleeding Kit**

A concern parents have is with putting their child’s health in someone else’s care, and there are many instances where this is the case. Therefore, it would be useful for a child to have an emergency bleeding kit in their vicinity at all times. Schools are becoming more equipped with needed resources to address bleeds. Many schools have nurses available or teachers trained to respond to an emergency situation. There are also protocols to ensure a safe and effective method is being followed.

**Education on WAS**

Existing educational material on WAS is predominantly based on the genetics behind the syndrome. As discussed earlier, this may include the mutations in the WASP protein (Jin et al., 2004) or articles that discuss the results of different forms of treatment (Boztug et al., 2010). The information that is available is hard to comprehend, even for myself. Mostly since it involves scientific literature that families outside of the sciences are now familiar with. A lack of knowledge and resources can be a contributing factor as to why parents have concerns leaving their children or why there is no understanding of WAS among a patient’s peers. Education on WAS can be provided in a variety of ways. This may include, having handouts that summarize what the syndrome is, who is affected by it, and how they are affected. Having presentations that demonstrate how to properly attend to a Wiskott patient’s medical needs. Or providing free online health seminars for Wiskott friends, families, and peers. Doing so will ensure Wiskott families are kept up to date on current research and opportunities to better their Wiskott child’s health. These educational opportunities will provide the one thing families are most wishful of, hope. That is,
hope that their child’s medical condition will be more attended to in the near future. Hope that research and treatment methods are progressing in the right direction. Hope that schools and institutions that care for these children are skillfully trained to attend to the child’s needs. And hope that individuals around the Wiskott child are aware of the signs when emergency assistance is needed. The question that this all comes down to is what will stimulate these educational motives? Until one engages with a Wiskott child, they may not be aware that the syndrome exists.

Without a basic introduction to the syndrome, individuals would not be aware of the affect it has on the Wiskott patient, or the steps they can take to assist. It is crucial for WAS families to be adequately educated on the syndrome, so they know how to address common symptom-related complications. Which led me to question what is missing and what questions need to be proposed to further address WAS. Such questions may include, are individuals aware of health-related certificates they can receive once completing training on bleeds? Are schools enforcing emergency kits to be readily available in all classrooms? A lack in information will only result in a lack in understanding the syndrome. More efforts should be made to ensure Wiskott is more known and better addressed.

My hope with this project was to create tools to address the needs that families, patients, and education staffing will find to be most useful when needing to comprehend WAS. The products include a handout, survey, and two presentations on emergency bleeding kit supplies and managing bleeds. The handout provides instructions on how to properly address a nosebleed, treat bruising, as well as information on when to seek medical emergency care. All of these steps are meant to ensure a child is well taken care of in the case of a serious bleed (Figure 1). For further recommendation, the handout can be edited to ensure the most recent information is being shared with the public. For example, are there new techniques for managing bleeds? The
public health impact this handout can have is to educate individuals on WAS in a concise format. The survey allows Wiskott families to respond to a variety of questions that ask their comfort with being away from their child as well as their understanding of WAS (Figure 2). A recommendation for the future is to also survey Wiskott families on how well information had been presented. For example, individuals may be asked to complete a quick survey after a Wiskott-related event to ask how the event could have been improved or what the individuals liked most. The public health impact this could have is making direct changes to the information being presented based on how the individual is receiving the information. An emergency bleeding kit is composed of items that can quickly address a patient’s bleed. EMTs are usually first thought of when needing an emergency medical response team, but I came to thinking, “Why can’t parents and teachers do the same”? That is, why is it that we immediately call emergency services for bleeds that can be properly attended to by anyone with simple training. The public health impact this would have is not only to save time, but also to save a life. The emergency bleeding kit that I created has items that include common over-the-counter medications and ace wraps that hold items in a certain position. An audio presentation has been created to instruct users on the different supplies, as well as how to use them properly (Figure 3). Wiskott patients are known to be more prone to bleeds, which is why I found it to be important for their peers to be informed on the best practices to manage and respond to any bleeding incidents. I created a “managing bleeds” presentation to inform the public on common injuries Wiskott patients may endure as well as the best ways to address these injuries in a timely manner (Figure 4). Similar to the handout, these two presentations are able to demonstrate the different supplies and techniques needed to manage bleeds. The presentation differs in the sense that it also includes images of some of the supplies, making it easier for families to identify when
needing to put their own kit together. The impact these presentations have is making the process of creating your own emergency kit slightly easier since everything is listed with instructions on how and when to use each item.

**Conclusion**

Though my ILEX is a research project on what information is currently available, it is also an analysis on what information is lacking in regard to WAS. As stated, most published articles on WAS have to do with the science behind the syndrome. That is the genotype, phenotype, and mutation in protein synthesis that results in WAS. Though these are all important to know, the focus of my APEX internship and ILEX paper is to draw attention towards the everyday people that are affected by the syndrome. What information is comprehensible for the average person that may be outside of the sciences? Are articles stating useful techniques or equipment to address bleeds? Though information is available, it is hard to find. The average individual may not be aware that the Wiskott Aldrich Foundation exists. Especially if never hearing of the foundation before. The average individual may also not be aware of the grants that are allocated every year for an Wiskott patient to pay for medical needs. The approach of both my internship and this project was to create what is not already published today. That is, create products that summarize WAS for family, friends, and peers. Create audio presentations that describe the different components that can make up an emergency bleeding kit. When becoming aware of a child’s high likelihood of experiencing a bleed it is important for families to be well-prepared for a situation to occur at any given moment. The next step should be to continue questioning what more can be done to better our future. “What resources would be most useful for families to have readily available at all times”? Being most prepared with the understanding of WAS and with the supplies
to respond to a bleed is essential when knowing a Wiskott patient since many symptoms can be life-threatening.
Appendix

Bleeding and Wiskott-Aldrich Syndrome (WAS)
or X-linked thrombocytopenia (XLT)

**CHILD’S NAME:**_________________

Emergency Contact Information:

Allergies/Restrictions:
What is WAS and XLT?
Wiskott Aldrich Syndrome (WAS) is an immune system (immunodeficiency) and blood disorder that increases the risk of severe infections and bleeding. Some people have a milder form of the disease called X-linked thrombocytopenia (XLT), which puts them at increased risk of severe bleeding.

What are the risks of having a low platelet count?
Having a low platelet count places individuals with WAS or XLT at high risk of severe bleeding or hemorrhage since platelets are what help stop bleeding.

What is the treatment for a low platelet count?
- Medications
- Avoiding contact sports
- Platelet transfusions

How do I/we keep my child safe/ How can bleeding be prevented? What activities are to be avoided?
- Wear protective gear when engaging in physical activities (helmets, elbow/knee pads, etc.)
- Avoid contact sports
- Have supervision when physically engaging with others
- Play on soft surfaces like sand, wood chips, and rubber mats when possible

What are some common symptoms of bleeding in WAS/XLT? How to recognize a bleed?
In addition to the sight of blood, look for signs of what may cause a bleed. These may include:
- Pain
- Bruising
- Complications with a specific area of the skin

How do I treat commonly occurring bleeds in my son?
Nosebleed instructions:
- In the event of a nosebleed squeeze the soft part of the nose (nostrils) together and hold as much pressure as he will allow. Hold for at least 7 minutes without letting go. Keep holding until it stops.
- Do not tilt head backwards and do not hold the nose at the top bridge
- Apply ice gently to the top bridge of his nose- this can help to stop the bleeding
- Call emergency contacts in order listed above
**Falls/Brusing Instructions:** Children with WAS or XLT that experience a fall are more likely to have bleeding under the skin or bruising than seen in other children. If a fall or bruising occurs:

- Apply ice immediately
- Call emergency contact in above order if significant fall/bruise occurs

**When do I seek medical emergency care (911 or what is applicable locally)?**

- If a significant fall occurs
- If the child’s experiences prolonged bruising

**Emergency Situations**: If you are concerned that an emergency situation *like a fall or bleed that is hard to stop* has occurred, call the child’s *emergency contacts in listed order* or call 911 (depending on severity).

When experiencing an emergency situation, there are a few ways to effectively address a bleed. These include:

- Apply direct pressure to the site of the bleed
- Raise the wound above the heart (if possible)
- Apply ice
- Tightly wrap the area
- *Call emergency contacts in listed order*

Figure 1: Handout
Pre-Survey Wiskott Aldrich Foundation

Hello, my name is Naomi Tesfaiohannes and I am an intern with the Wiskott Aldrich Foundation. I am currently pursuing an MPH in Community and Public Health at the University of San Francisco. I am putting together a pamphlet on the bleeding risks associated with Wiskott Aldrich Syndrome (WAS) and X-linked thrombocytopenia (XLT) and how to manage the bleeds. This could be a useful tool for caregivers, as well as to share with family, babysitters and to schools to help them provide better care for your child.

Before distributing the pamphlet, I would greatly appreciate if you could take a few minutes to complete this pre-survey. The purpose of this pre-survey is to understand what families are looking for in a pamphlet on bleeding in WAS and XLT. Thank you for taking the time to provide feedback on this pre-survey!

* Required

1. Email *

Wiskott-Aldrich Foundation
2. Age group of the individual with WAS or XLT
   Mark only one oval.
   - 0-5 years of age
   - 6-11 years of age
   - 12-17 years of age
   - 18+ years of age

3. Do you identify as a:
   Mark only one oval.
   - Parent/ Primary Caretaker
   - Family Friend
   - Other Family Member
   - Patient
   - Other: ________________________________

4. Do you believe to have a strong understanding of WAS or XLT and how it affects a patient?
   Mark only one oval.
   - Definitely
   - Somewhat
   - Not at all

Figure 2: Survey
Emergency Bleeding Kit Supplies

Naomi Tesfaiohannes

Figure 3: Emergency Bleeding Kit Presentation

Figure 4: Managing Bleeds Presentation
CEPH Foundational Competencies

<table>
<thead>
<tr>
<th>Competency</th>
<th>Choose at least 2 foundational competencies and briefly note why you feel it is relevant to your ILEX paper or presentation. (Note: all students can choose Competency #19, and mention your specific audience)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence-based Approaches to Public Health</td>
<td></td>
</tr>
<tr>
<td>1. Apply epidemiological methods to the breadth of settings and situations in public health practice</td>
<td>Throughout my time as a master’s student, I have become very aware of ethics, especially when conducting research with human participants. There are epidemiological methods that all researchers must follow to protect the private information of its study participants. The same applies for my ILEX paper as I will be reviewing information on Wiskott Aldrich Syndrome (WAS) individuals.</td>
</tr>
<tr>
<td>2. Select quantitative and qualitative data collection methods appropriate for a given public health context</td>
<td>This will be done by determining how WAS information is collected and analyzed. Are resources readily available for Wiskott families? For example, is this via a questionnaire or interview-style?</td>
</tr>
<tr>
<td>3. Analyze quantitative and qualitative data using biostatistics, informatics, computer-based programming and software as appropriate</td>
<td></td>
</tr>
<tr>
<td>4. Interpret results of data analysis for public health research, policy and practice</td>
<td>This will be done by reviewing previous studies and articles that address WAS or WAS related resources.</td>
</tr>
<tr>
<td>Public Health &amp; Health Care Systems</td>
<td></td>
</tr>
<tr>
<td>5. Compare the organization, structure and function of health care, public health and regulatory systems across national and international settings</td>
<td>I plan on doing so by reviewing the political, health care, and school-based resources for WAS patients and their families to be provided needed attention, especially when experiencing a medical emergency.</td>
</tr>
<tr>
<td>6. Discuss the means by which structural bias, social inequities and racism undermine health and create challenges to achieving health equity at organizational, community and societal levels</td>
<td></td>
</tr>
<tr>
<td>Planning &amp; Management to Promote Health</td>
<td></td>
</tr>
<tr>
<td>7. Assess population needs, assets and capacities that affect communities’ health</td>
<td></td>
</tr>
</tbody>
</table>
8. Apply awareness of cultural values and practices to the design or implementation of public health policies or programs

9. Design a population-based policy, program, project or intervention

10. Explain basic principles and tools of budget and resource management

11. Select methods to evaluate public health programs

**Policy in Public Health**

12. Discuss multiple dimensions of the policy-making process, including the roles of ethics and evidence

13. Propose strategies to identify stakeholders and build coalitions and partnerships for influencing public health outcomes

14. Advocate for political, social and economic policies and programs that will improve health in diverse populations

15. Evaluate policies for their impact on public health and health equity

**Leadership**

16. Apply principles of leadership, governance and management, which include creating a vision, empowering others, fostering collaboration and guiding decision making

I will include sections in my ILEX paper that discuss ways schools can better prepare for a WAS child’s sudden bleeds. The principles of leadership will be reflected through my APEX products as I created handouts and presentations on useful resources and steps that individuals can use to address an emergency bleed. Principles of leadership will also include voicing concerns to local and state leaders, drafting petitions, and contacting local news castings to report on WAS and its symptom-related complications

17. Apply negotiation and mediation skills to address organizational or community challenges

**Communication**

18. Select communication strategies for different audiences and sectors

19. Communicate audience-appropriate public health content, both in writing and through oral presentation

This will be done either via a recorded presentation or in-person during Health Profession’s Day.

20. Describe the importance of cultural competence in communicating public health content
### Interprofessional Practice*

<table>
<thead>
<tr>
<th>Competency</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Perform effectively on interprofessional teams</td>
</tr>
</tbody>
</table>

### Systems Thinking

<table>
<thead>
<tr>
<th>Competency</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. Apply systems thinking tools to a public health issue</td>
</tr>
</tbody>
</table>

### MPH - Community and Public Health Practice Competencies

<table>
<thead>
<tr>
<th>Competency</th>
<th>If CPHC is your program concentration, choose at least 2 competencies you plan to draw on and mention how it is relevant.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Apply qualitative methods to assess community assets for addressing public health and environmental issues</td>
<td>The focus of my ILEX paper is to review the lack of resources readily available for parents, teachers, and WAS patients when looking at the educational understanding or equipment readily available for patients.</td>
</tr>
<tr>
<td>2. Analyze how issues of power, race and ethnicity, sex and gender identify, and socioeconomic factors affect the development, implementation, and evaluation of community-based projects</td>
<td>My research project proposal will address this public health problem by integrating products I created throughout APEX as well as research from literature reviews on WAS as a whole.</td>
</tr>
<tr>
<td>3. Develop a research project proposal using mixed methods to address a public health problem</td>
<td></td>
</tr>
<tr>
<td>4. Apply project management strategies to improve the quality of programs and services in public health settings</td>
<td></td>
</tr>
<tr>
<td>5. Identify environmental health risks in vulnerable communities and examine strategies to reduce exposures</td>
<td></td>
</tr>
</tbody>
</table>

Figure 5: MPH Competencies
References


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