Combating stigma in infectious diseases: A scoping review of de-stigmatization campaigns

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Abstract

COVID-19 has put a spotlight on stigma and the effects it has on infectious diseases. The world has seen and recorded the stigmatization of people that were associated with a race or specific population. However, this notion of stigma and infectious diseases is not a new phenomenon. It has existed through most of human history as this scoping review will show through the examination of three infectious diseases: Tuberculosis, HIV/AIDS, and SARS. Previous research will show that many researchers have focused on a specific issue involving stigma in each of these infectious diseases. This scoping review will allow for a collection of information and research while consolidating the findings to help with understanding the forms of stigma that affect people with the diseases and the initiatives that have been taken to de-stigmatize them. The data in this scoping review was collected was through a title search using key terms, and once journal articles and grey literature was found, a snowball method was used by going through the bibliography and the text itself to find other articles that would be beneficial to the research. The results that the research produced was in the form of six observations that could be used for other infectious diseases and pandemics. The findings also showed a need for better education and support towards those that have been stigmatized in order to address the issue at the root of the problem. Effective de-stigmatization was found to be a result of both public education using factual information and community support/outreach to stigmatized communities through dialogue. Such findings may point other researchers and public health officials to further investigate these methods of de-stigmatization. Finally, addressing stigma in infectious diseases may help improve treatment rates, which can lower infect rates and death rates.

Keywords: stigma, de-stigmatization, discrimination, education

Introduction

COVID-19 has had a profound effect on all aspects of life around the world. COVID-19 has been able to change government policy, impact most countries' economic situation worldwide, and have changed many people's lives. A significant change that COVID-19 has exacerbated is the stigma of being East Asian or looking like an East Asian. Many Asian people have faced racism, discrimination, and stigma due to COVID-19. However, such a stigma is not new as other infectious diseases have also brought the same stigma to different groups of people before. Infectious diseases have been around since the beginning of human history. When someone was infected and was seen by others as "different," they were exposed to stigma by the community and were shunned or isolated from society. While many studies and articles have examined the physical, medical, or pharmaceutical actions against a pandemic, such as the efficacy rate of quarantine or wearing a mask, this study aims to look at the social actions that could be taken to help people. Stigma has a powerful effect on someone's life. It can destroy social and economic status and create mental health issues such as depression, anxiety, and low self-esteem. The most recent example of this is with COVID-19. When COVID-19 was first announced to have come from China, the first thing that was thought of by many Chinese was the memories of the 2003 SARS outbreak. In 2003, the Chinese population was heavily affected by stigma because of the misconceptions and misconstrued pieces of information used to portray Chinese people. The same thing happened with COVID-19, but as the research shows, the people responded faster as many learned their lessons from SARS. Other infectious diseases that have caused similar stigma is Tuberculosis (TB) and HIV/AIDS. By examining TB, HIV/AIDS, SARS, and COVID-19, the review can identify the stigma that was shown towards people with the disease, the actions used to de-stigmatize, the lessons learned, and recommendations for responding to the next infectious disease.

This study was undertaken in order to consolidate research on stigma and infectious diseases, specifically stigma seen in Tuberculosis, HIV/AIDS, and SARS. While these three are the main area of focus, COVID-19 is also discussed as the research presented can be related to the present situation. This study aims to answer the research question, "What are some lessons learned from previous campaigns to fight the stigma of infectious diseases?" Furthermore, the sub-questions that will be explored are as follows:

- Who is perpetuating the stigma, and who is victimized
- Who is behind the development of the initiatives/interventions, and what were they?
- - How successful were they in fighting the stigma at the time; did they achieve their goals locally?
- To what degree did this influence or address stigma more broadly? What, if any, lasting effects of stigma were there over the medium and long term?

In order to answer these questions above, the paper will begin with a background section that contains information regarding the origins of stigma, the different types of

stigma, the research that has been done so far on stigma, infectious diseases, and the stigmatizers, along with the campaigns and initiatives that have been used to de-stigmatize infectious diseases. The background chapter will provide the necessary information to understand where the stigma comes from, how stigma is projected upon people, and how the stigma is reduced. Additionally, the sections on Tuberculosis, HIV/AIDS and SARS will include a background portion because understanding where the disease comes from and the effects they have on people will help further the understanding of the stigma that a person experiences when they have such a disease. For example, with SARS, one of the symptoms that it produces is coughing, and it originated from China. These two facts can help establish why somebody may be subject to discrimination or stigma on a New York Subway train when they cough and they appear to be Asian. Another example of the necessity of having this section here is with HIV/AIDS, where it is discussed how the disease originated in Africa through monkeys, which helps establish why many Africans face stigma regarding HIV/AIDS.

After the background chapter, the paper will move towards the three chosen infectious diseases that will be analyzed to answer the research questions. The infectious disease chapters will follow the same structure of the review by having a background section that will contain a history of the disease, which will be followed by the effects of the disease on the person. The infectious disease chapters will finish by examining the stigma perpetrated on people due to the disease and the de-stigmatization campaigns and initiatives that have been taken to address stigma with each specific disease. The order in which the diseases will be examined will be Tuberculosis, HIV/AIDS and then SARS. These three chapters will demonstrate the kinds of stigma in each disease and how they respond to them. This will allow for a comprehensive examination of the lessons learned, which can help identify who has developed the initiatives and the success achieved, either short term or long term.

Once the three infectious diseases have been examined, the discussion chapter will consolidate the findings and use the identified observations to apply them to the present case of COVID-19. The observations that will be examined will work around the ideas about the necessity of education for de-stigmatization, community outreach, the lack of actions in Quadrant I & IV in De-Stigmatization chart which will be used to chart the different initiatives and will be introduced later on, the need for support to those that are stigmatized, the lack of historical campaigns, and the use of social media. Finally, the paper will conclude with summary the findings and the paper.

This study was undertaken to better comprehend what has been done in the past and what is currently done for de-stigmatizing infectious diseases, while also consolidating the lessons learned and the past identification of stigma to help prepare for the future. It is vital to understand this knowledge because stigma plays an active role in the work emergency managers, public health officials, and government organizations do when controlling the general public's reaction to emergencies, such as pandemics. Even though this study focuses on infectious diseases, some of the concepts, lessons learned, and ideas on how to de-stigmatize can be transferred to other events or topics, such as Post Traumatic Stress Disorder

(PTSD) and mental health after a catastrophic natural or human-caused disaster, or a humanitarian crisis such as refugee migration. The study also provides value-added to understanding an individual or community's social needs when they are affected by an infectious disease. As well, the importance of this research stands out when it comes to public health. By understanding the impact, we can examine the disease and the stigma it brings to people more holistically. The holistic approach is used when examining the physiological, economic, and gendered effects since people may understand both sides of the same story. It is necessary to find the root cause of people's feelings and why specific interventions are used. For example, people with TB may have an issue with taking the necessary medication, leading to TB getting worse. As a result, TB clubs were created to ensure patients were supported to adhering to the medical regimen. Stigma creates more harm since fewer people seek medical attention, there is lower case reporting, adverse mental health impacts arise in those stigmatized, and people are non-compliant with public health guidelines, which all increases the spread of disease (Mamuji, 2020).

Introduction to case studies

The research aims to look at three infectious diseases: Tuberculosis (TB), HIV/AIDS, and SARS, to examine initiatives undertaken to address the stigma associated with these diseases as they have caused specific groups of people to be stigmatized once infected. These three infectious diseases were chosen based on the relevance of the disease to modern society, the available research, and the historical aspect of each of the diseases. TB, HIV/AIDS and SARS allow for a timeline to be established historically, starting with TB, transitioning to HIV/AIDS, and then ending with SARS. There was a notion of using the Spanish Flu of 1918, but the limited number of journal articles available for sufficient research was not found and as such proper research was unable to be completed. Furthermore, the three infectious diseases are chosen for more specific reasons. TB and HIV/AIDS were chosen as they have a long history of infecting people, but at the same time, their effects on society are still seen today. TB and HIV/AIDS are not like SARS, which was short-lived; the stigma that people experience is still seen today and mapping out what has been done in the past and understanding the lessons that were learned can help with future de-stigmatization. SARS, on the other hand, is relatively recent. However, it is one of the first significant pandemics that we see after the 1918 Spanish Flu. SARS is also one of the most recent examples of where stigma may have occurred regarding infectious diseases. Finally, one of the reasons SARS was chosen is its ability to connect with the current situation of COVID-19. SARS and COVID-19 are connected through the stigma that was placed on East Asians at the beginning and during the outbreaks of both diseases. When COVID-19 began, many of the lessons learned from SARS were revisited to help with de-stigmatizing COVID-19.

While stigma may be associated with a physical deformity, it is also found in the causes of infectious diseases. For example, Somma (2008) researched stigma in Bangladesh, India, Malawi, and Colombia on TB. They found that if a woman told others, she had TB, she "would be branded as a TB patient for life." (Somma 2008, pg. 830). With SARS and

HIV/AIDS, Des Jarles (2006) stated that both of these diseases were new, but they had an association with “stranger” groups such as gay men and injection drug users for AIDS, Asians in general, and Chinese in particular for SARS” (pg. 563). These infectious diseases caused people to suffer socially, economically, and mentally, so it is vital to properly understand stigma and its effects to identify it earlier and act with better precision when dealing with stigma.

Methods

The research method chosen for this study is a scoping review because it allows for the rapid mapping of previously conducted research on a specific topic or area of focus (Arksey & O’Malley 2002). The scoping review will first have a research question as outlined above, and will then be answered by finding relevant articles through multiple sources, including online scholarly journals, government reports, news articles, and grassroots campaign reports. The protocols in place are to first gather data through a title search and a quick review of each of the abstracts or introductions to either take away or keep the source as a valid source. Some of the terms used were discrimination, stigma, prejudice, SARS, HIV/AIDS, TB, Tuberculosis, de-stigmatization, and campaign. These terms were used in different combinations in order to find as many sources as possible. This type of search will allow for as much information to be gathered and then look at keywords to expand or narrow the search field. Finding articles from both scholarly and grey literature will be done by using a list of key terms that will expand or narrow the search. As more articles are found, the list of key terms used in the title search will change to gather as much relevant information as possible. For the purpose of the study there were 26 articles and resources used for the background section, 31 articles and resources for the TB section, 40 articles and resources for HIV/AIDS, and 25 articles and resources for SARS and COVID-19 combined. The themes looked at to determine if an article or resource could be used were based on the research questions such that every article used was able to contribute to answering part of the questions. Any article containing paraphrases or direct quotations that were useful to the research were explored further. This method helped expand the research web through the snowball method, where one article led to another until it stopped.

The literature about these three diseases were searched using a ‘snowball sampling’ method, which took the references of one article and used it to find other relevant articles that would add to the research. The literature was then examined and sorted by identifying if they described the stigma imposed on people or if any campaigns or actions took place to assist with de-stigmatization.

The search for such sources were done on Google Scholar, Ommi, Web of Review, Google, and JSTOR. The search was expanded to other journals such as medical journals or Social Science and Community Development journals that prove relevant to the research. As the research progressed, other sources were looked at to capture as much information as possible, as needed.

This study contributes to the research being conducted by Professor Aaida Mamuji and Professor Jack Rozdilsky entitled *Destigmatizing Chinese Communities in the face of COVID-19: Emergency Management Actions to Address Social Vulnerability in Toronto and Nairobi*.

Limitations

Such results of which types of stigmas are found and recorded are not an absolute indication of the reality as this scoping review captured a limited number of studies and has used a limited number or methods of categorization. As this is a scoping review, the pool of references are relatively limited and if further research is done other types of stigma, as listed in the background section, could be found and more examples could be used. Further, the findings shown by the three different chapters do not suggest that stigma is only found in such settings. Many articles have not been discovered through this process, and there are many more instances where stigma may not be recorded or recognized by an academic paper or society itself.

It will be essential to further this scoping review by diving deeper into the research articles that pertain to these infectious diseases and to continue to do new research on different infectious diseases other than TB, HIV/AIDS, and SARS. The research also showed that many of the campaigns that are known come from the West and as such raise crucial benchmarks for what has been done, but it also shows the limits of the research. Further research is needed in Asia, Africa, and the Middle East where the culture of stigma and the understanding of what is needed to address stigma is also different. For example, many campaigns that were readily available in scholarly articles or online resources about HIV/AIDS came from a Western perspective, and not many articles touched upon the issues and stigma that occurred in the East.

Overall, the research that is used comes from academic or verified sources. However, the limitation of the research done within this scoping review is that the literature used may only be a fraction of the research published to understand stigma and the campaigns and initiatives used to de-stigmatize infectious diseases. Due to the constraints of a scoping method, not every article was explored, and as such, some information may have been left out that could provide a more detailed picture of stigma and the three infectious diseases.

Background

The background section will provide an overview of important information about the origins of stigma, the different types of stigma, where one may find stigma, and its effects on a person. It will then identify the research done on stigma in different fields of study and the initiatives that were undertaken to address the stigma associated with Tuberculosis, HIV/AIDS and SARS. This section of the research paper is necessary to understand the stigma perpetuated by others onto those with an infectious disease. The reason for this is understanding the past can help us understand the future. The origins of stigma first show how the idea of "stigma" was developed, helps define critical terms such as discrimination, prejudice and stigma. This will help identify the different types of behaviour that people face or the different areas that specific actions or initiatives try to tackle. Understanding the stigmatizers is also a key component when identifying stigma as different people will have different reasons for stigmatizing others. It may be due to a lack of information or a cultural upbringing that affects the perceptions of the stigma. This is important to note because de-stigmatization campaigns and initiatives can work to change such perceptions and understanding this part ahead of time can create a better picture of where such actions for each of the three diseases originate.

Origins of Stigma

Historically, people have used stigma to identify people to discriminate against from a social-economic standpoint. Stigma occurs when people have been 'marked' due to an illness or physical impediment that makes them look different or act differently from what is considered the norm in a given context. Courtwright (2010) supports this idea by explaining that the process of stigmatization "begins when a particular trait or characteristic of an individual or group is identified as being undesirable or disvalued, and the individual adapts self-regarding attitudes such as shame, disgust, and guilt" (p. 35). This topic of a mark will be discussed further in other sections for it will be essential to recognize that the physical marks transition and transform over time.

The origins of stigma being a 'mark' on people come from the Ancient Greek root word *Stig* which means to prick or puncture (Tyler, 2020, p.i). This originally referred to tattoos or permanent markings made with a hot iron that a criminal, traitor, or slave would be branded with (Barrett & Brown, 2008), and was "usually a sign of degradation" in Ancient Rome and Greek cultures (Jones, 1987, p. 143). Criminals and slaves at that time were usually looked down upon, and to have such a marking on one's body signalled to everyone that they were not in the same social class as everyone else. Jones (1987) states: "Like tattooing, the branding of humans had more than one function, though the predominant one was penal" (p. 152). This act of degradation was found as early as the Neo-Babylonian period and Pharaonic Egypt (p. 152), which suggests that others' marking of one's body has existed since the early formations of civilization.

The act of marking one's body to symbolize an individual status or as a punishment for a crime is the early form of stigma directed at people of different classes or social standing. The ancient form of stigma was a physical mark that could be seen and was typically permanent. Ancient Greece and Rome were not the only cultures to associate stigma with a physical marking such as a tattoo. In Asia, primarily in Japan and South Korea, tattoos were seen in the same regard. The earliest record of tattooing in Japan was in 5000 BCE, which was captured by a Chinese Scholar. By 720 CE, "tattoos were used as punishment for criminal activity rather than an art form, with Japan adopting similar attitudes to the Chinese seeing tattoos as barbaric" (MacFarlane, 2019, p. 4). Even today, the criminal syndicate such as the Yakuza uses tattoos to identify oneself to the organization (MacFarlane, 2019, p.4). The word stigma has had its meaning deeply embedded in the physical history of tattoos and brands in the Western World and Eastern cultures.

In contemporary times, a mark of stigma may not be physically present, as seen in tattoos or brands Much rather stigma, or a mark, may be seen when "elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold" (Link & Phelan, 2001, p. 367). Within Link & Phelan's definition, there are still attributes of a 'mark' left on a person. Still, it could be better described as an "attribute that is deeply discrediting," and that reduces the bearer "from a whole and usual person to a tainted discounted one" (Goffman, 1963, p. 3). Furthermore, this form of stigma is further described as "a characteristic of persons that is contrary to a norm of a social unit" where a "norm" is defined as a "shared belief that a person ought to behave in a certain way at a certain time" (Stafford & Scott, 1986, p. 80-81 as cited in Link & Phelan, 2001). Another definition of stigma is that "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (Crocker et al., 1998, p. 505). While Goffman's and Crocker's definitions of stigma are valuable and begin to move away from the physical aspect of stigma or tattoos, it still has a physical attribute that shows a specific type of unwanted behaviour not a part of the norm of society. Link and Phelan (2001) begin to move from a physical notion of stigma by exploring how dominant cultural beliefs can link a person to negative stereotypes and how labelling human differences are entirely based on how much social, economic and political power are placed behind the identification of differences. (pg. 367)

A comprehensive and holistic approach to stigma will be more suitable for examining stigma since it is not only about the physical appearance or the physical behaviour of an individual or a group of people, but it is an involuntary separation between society and that specific group of people or the person. The separation of the individual or group can be seen in many ways. For example, the "dominant" group can create stigma through their actions or what they project onto the stigmatized group. This is the current model for researching stigma, which looks at the different intersections of stigma, discrimination and prejudice.

Some may use the words discrimination or taboo in place of stigma, but each term is slightly different. Discrimination is defined as "unfair treatment due to a person's identity"

(CMHA, 2020), whereas stigma is defined as "the negative stereotype and discrimination behaviour that results from this negative stereotype." (CMHA, 2020). On the other hand, a taboo is something that is "an 'unthinkable' action" (Fershtman et al., 2011, pg.139). In this instance, a taboo is an action that is not socially acceptable, such as incest or cannibalism. Another word that is often used is prejudice, which is an "Agreement with a belief and/or negative emotional reaction (e.g., anger, fear)" (Corrigan & Watson, 2002, pg. 16). The difference between prejudice and stigma is that prejudice derives from stigma, and it is the agreement of an emotion that causes stigmatization of a person. Prejudice and discrimination are also different as prejudice is an unjustified and incorrect attitude towards a person or people due to their association with a social group (Mcleod, 2008). For example, somebody may have incorrect assumptions about women, leading to sexism or being sexist. Discrimination, on the other hand, is only the negative behaviour of a person towards another person. Somebody can have prejudice but not discriminate, while at the same time it is possible that somebody may discriminate due to prejudice. Stigma, prejudice, and discrimination are all linked together as prejudice and discrimination are caused by stigma in most cases. On the other hand, taboo is often linked with these terms because once somebody does an action that is deemed to be "taboo" by the community, stigma, discrimination, and prejudice may be directed at that person or group of people.

The form of stigma, discrimination, prejudice or what is deemed taboo will vary between cultures and countries. Some things are considered socially acceptable in some parts of the world, but are considered socially unacceptable in other parts. Since each person, culture or society has different beliefs, it is evident that stigma could be found in many different places and settings, but can occur in all aspects of life. This paper will look into how stigma can affect infectious diseases and how stigma is combated with various campaigns or initiatives. Since the examination of stigma be one of the core components of the research, it is essential to define what stigma is and how it relates to other words that have a similar definition as then can be often used interchangeably, but stigma, in particular, has a specific definition as to what is being caused to a stigmatized person. This research that has been conducted will examine how stigma is identified and how discrimination and prejudice can affect one's perception of another, leading to stigmatization.

Research on Stigma

The research on stigma can be found in many different disciplines across an extended duration of time. Erving Goffman researched stigma in 1963, and Gordon Allport in 1958 (Stuber et al., 2008). The original research that was conducted reflects the individual experiences and the interactions between the individual and the community, and the subjects with "unusual conditions such as facial disfiguration, HIV/AIDS, short stature and mental illness" (Stuber et al., 2008, pg. 2). Both researchers found that the research discussed the "exposure to negative attitudes, structural and interpersonal experiences of discrimination or unfair treatment, and violence perpetrated against persons who belong to disadvantaged social groups" (Stuber et al., 2008, pg.2). Goffman and Allport's research had different results when looking at stigma. Research at that time on stigma focused on the "enforcement

of social norms and disease avoidance while prejudice and discrimination were more about exploitation and domination (Stuber et al., 2008, pg. 2). As such, the research on stigma was different as it did not show the "implications of gender, age, race and class divisions" (Stuber et al., 2008, pg. 2). The separation of stigma from prejudice and discrimination studies created holes in the research since it would miss critical dimensions that both studies would need to be holistic.

As we moved away from the civil rights movement of the 1960s, it became evident that research in this field could not just look at the implications of racism or equality, but had to include the unconscious forms of bias, which is how the modern form of research is formed (Stuber et al., 2008). There was a need to understand stigma and prejudice together, and the first research in this combined field was on tobacco control policies and the understanding of the effects it faced in China (Stuber et al., 2008). With this first step, clarity was introduced about how stigma, prejudice, and health could be linked with further research, but more research is needed to ensure that the clarity of this steam is fully explored. It is important to note that Link and Phelan have been the pioneers in this type of research, and their research is often quoted by new researchers. Other research that has been done is the internalization of stigma and its effects on mental health. The current research and experts suggest that while the combined research has created creative and innovative ways to "reduce the impact of prejudice and stigma for heath or to redress stigmatization and prejudice and their root causes" (Stuber et al., 2008, pg. 8), much more has to be done to understand how prejudice, discrimination, stigma and health all intersect and interact with society.

Typology of Stigma

Stigma can manifest itself in different ways and can be shown in other contexts. Stigma can affect an individual in multiple ways, especially when it comes to being out in public. The public is usually where a person is exposed to potential situations where they may be stigmatized because everyone can see them. This potential exposure to stigma may lead people to avoid going out in public to avoid unwanted attention. The stigma that could be encountered can be separated into different types of stigma based on its effect and who is stigmatizing the infected person or people who may have TB, HIV/AIDS and SARS. The importance of understanding the typology of stigma is to identify where the stigma comes from and what barriers stigma may construct for the stigmatized. In Goffman's (1963) book "*Stigma notes on the management of spoiled identity*," he described three categories of stigma in different works. The first is the "abominations of the body," the second is the blemishes of individual character, and finally, tribal stigma (pg. 4). In other words, Goffman has described stigma as "various physical deformities", "radical behaviour and stigma transmitted through lineages which can contaminate all members of a family" (pg. 4). In this instance, stigma is primarily a set of undesirable traits or beliefs put towards a set of people. As Goffman (1974) described, the undesirable qualities range from physical to mental and even passed through family teachings. Goffman's three categories of stigma are furthered by Rachel Grappone (2020) from The National Alliance for Mental Illness.

Grappone (2020) further breaks down three categories of stigma that Goffman states in her work when she writes for the NAMIAdvocate. She describes seven different types of stigma that can be perpetuated by an individual or group upon another person or group of people. They are "public stigma, self-stigma, perceived stigma, label avoidance, stigma by association, structural stigma and health practitioner stigma" (Grappone, 2020, pg. 2). Each of these is described differently or between society and the stigmatized person or people. Her article describes how each form of stigma is described and what each form of stigma is. While most stigma types are associated with different individuals, the stigma by association or courtesy stigma affects the people related to or associated with the stigmatized person. The typology of stigma is essential to understand since it allows identifying stigma in society's social structures, as shown in Table 1. As such, each of the seven different types of stigma will be explained in more detail and will become how each of the four infectious diseases will be examined in Table 1. Table 1 was inspired by Grappone's (2020) work on the different categories of stigma, but the author of this paper, Nathan Yiu, developed the Table. The author took the categories and their descriptions from Grappone (2020) and modified it in order to fit the needs of the current project.

Table 1. Stigma Summary Grappone (2020)

	Where Stigma Occurs	**Stigmatizer**	**Who is Stigmatized**	**Consequences**
Public Stigma	Public spaces and private spaces	General Public	People with infectious diseases	Individuals or groups of people are separated from the rest of society and are targeted, leading to a lower quality of life for those stigmatized.
Self-stigma	Public spaces and private spaces	A person with an infectious disease	People with infectious diseases	Internalized stigma and can affect mental health and physical wellbeing.
Perceived stigma	Public spaces and private spaces	A person with an infectious disease	People with infectious diseases	The person with an infectious disease believes that others have negative thoughts or conceptions, leading to social distancing and withdrawal from society.

Label Avoidance	Treatment centres, Medical facilities, doctor's offices, etc.	General Public	People with infectious diseases	Those with stigma will avoid treatment, which can lead to infectious disease progress, which may be harmful as it can cause severe damage or even death. Diseases that could be cured may progress to an advanced stage due to label avoidance.
Stigma by association	Anywhere	General Public	Family, friends, coworkers or others that are working with or assisting someone with an infectious disease	People associated with someone that has an infectious disease are stigmatized. They are treated as if they also have the disease, or they approve of behaviour that may seem to lead to infectious diseases.
Structural stigma	Any place that may be under the jurisdiction of stigmatizing policies, laws or rules.	Social structures and people that create the stigmatizing policy	People with infectious diseases	Members of specific groups of people become stigmatized by policies that limit the number of opportunities.
Health practitioner stigma	Treatment centres, medical facilities, doctor's offices	Health Practitioners	People with infectious diseases	Patients with specific illnesses are treated differently by the health practitioner and are usually given procedures outside of the norm.

Public stigma is caused when the general public begins to adopt negative behaviour towards a specific group of people. Such behaviour can include discrimination, prejudice, negative stereotypes, fear, rejection and avoidance of specific people (Grappone, 2020). More specifically, public stigma is usually caused when the community sees a specific group of people within the community as different or possessing traits that are undesirable. While stigma is projected upon negatively stereotyped people, the stigmatized people may also face

prejudice and discrimination. The effects of the stigmatization of a specific attribute or multiple attributes of a person or a group of people can leave permanent scars or marks which are both seen and unseen. It can cause people to treat them differently due to the visible mark on these people. For example, people may have a public stigma towards others who have a mental health illness. They may avoid them in the streets and have misconceptions about why they act in a specific way or openly abuse and reject a person with mental health (Corrigan & Penn, 1999). Other physical marks that may be stigmatized could come from the result of the infection. For example, HIV/AIDS can cause severe physical weakness and a compromised immune system, changing a person's physical appearance. Such changes may be taken into account in the public, which may cause stigmatization from others. An example of a stigma leaving a physical mark would be the physical abuse directed at people living with HIV/AIDS in countries such as Lesotho, Malawi, South Africa, Swaziland, and Tanzania (Dlamimi et al. 2007). Victims reported that they received physical and verbal abuse because they were identified as somebody with HIV/AIDS. The nurses who cared for them also corroborated their claims (Dlamimi et al., 2007). Furthermore, with TB, after one recovers there may be permanent damage to the respiratory system, which may cause people to stigmatize that person as they are now marked as no longer able to perform their daily duties or regular job. Another example of public stigma is in the social context of everyday life. Today there is a stigma found at the workplace, in public and even in personal aspects of one's life. One of the examples is where:

> Women, racial minorities, and ethnic minorities who have obtained professional class or highly skilled occupations, either by inherited class privilege or social mobility, are usually unable to escape stigma and social markedness because their subjugated status is highly visible (Heller, 2011, pg.21).

The next example is where "African Americans who hold professional occupations feel that their intelligence, work ethic, preparation, and leadership abilities are regularly held in doubt by their white coworkers" (Bowser, 2007 as cited by Heller, 2011, pg.21). Both of these examples show that it is evident that anything could add to the stigmatization of an individual person or a group. A person's success, social mobility, class, or ethnic background can cause people to stigmatize certain people or a group of people due to a dislike or negative stereotype. It is also essential to make note that public stigma can incorporate the six other forms of stigma.

Self-stigma is when the person that is being stigmatized begins to take the stigma internally and begins to believe that what others are saying is true. They begin to prejudice, discriminate, and believe negative stereotypes about themselves as real (Grappone, 2020). There is another form of effect that affects stigmatized people, which is derived from differential treatment, and that is the deterioration of mental health and physical health due to stigma. Individuals that are stigmatized may have a disease or a mental health illness that affects them. Still, due to the stigma that others project upon them, it may lead to a sense of disvalue. They may adopt a "set of self-regarding attitudes about the marked characteristic that include shame, disgust, and guilt" (Courtwright & Turner, 2010, pg. 35). Furthermore,

those that are stigmatized can suffer from self-isolation since the stigma may "produce a set of behaviours that include hiding the stigmatized trait, withdrawing from interpersonal relationships, or increasing risky behaviour" (Courtwright & Turner, 2010, pg. 35). Being stigmatized may also make the person feel "that they are being labelled, stereotyped, or isolated from/by others, which may lead them to self-stigmatize. Self-stigmatization incurs negative beliefs about themselves, lose self-esteem and self-efficacy, and thus tend to isolate themselves from others, including their own in-group" (Sternke & Abrahamson, 2014, pg. 5).

Perceived stigma is a form of stigma that makes the person with a disease feel that others negatively perceive them (Grappone, 2020). Other effects of this type of stigma can be "status losses, and acts of discrimination are towards a stigmatized group" (Sternke & Abrahamson, 2014, pg. 6). It is also possible that life quality is lowered since they lose self-esteem and isolate themselves to avoid stigmatization. Such actions may also stigmatize people as "taboo" because their actions may be frowned upon or stigmatized due to what they believe. The effects of stigma can seem evident, especially when it comes to infectious diseases and mental illness. The topic of stigma and how it affects people is a topic that has become popular among researchers looking at the topic from different fields. Additionally, perceived stigma can lead to a person being "challenged doubly, and they struggle with the symptoms and disabilities that result from the disease. But also the stereotypes and prejudice that result from misconceptions about mental illness" (Corrigan & Watson, 2002, pg. 16). In reality, stigma can affect anybody since it is a negative stereotype projected upon people by a dominant group of people. Anything that may "offend" or invoke the feeling of disgust can cause stigmatization for the people who face this challenge. No matter what stigma is being projected or what type of stigma is being displayed, there are serious consequences or effects that a stigmatized person will have due to the projected stigma. Perceived stigma can lead to health issues similar to public and self-stigma. It can lead to those that are stigmatized feeling depressed and unwanted in a community.

Label avoidance is a form of stigma where the person with an illness will avoid getting treatment for their disease as they are afraid of being associated with such a disease (Grappone, 2020). The public usually projects label avoidance upon a group of people or individuals due to a specific difference. The person refusing to receive treatment refuses to be labelled as someone 'a part' of the group with such a disease. Label avoidance stigma can cause serious harm since stigmatized individuals may not seek treatment for an illness or may lose social interaction as described above. For example, some patients will avoid getting treatment for TB in Bangladesh and other Asian countries since it would automatically label them as a TB carrier (Somma et al., 2008). This is very harmful to efforts to reduce the rate of infection and label avoidance stigma that may cause treatable infectious diseases to become drug-resistant and harder to address adequately.

Stigma by association is different from other forms of stigma since the stigmatizer does not target the infected person, but rather the people associated with the ill are stigmatized (Grappone, 2020). Family members, friends, coworkers and even strangers trying to help the ill person can be stigmatized because the public sees that they are within the same

social circle. Often, the ‘dirty’ work is associated with helping, or the person who is assisting with caring for a person, has lowered themselves to a lower health bracket or approve of a particular behaviour or lifestyle (Phillips & Benoit, 2013). An example could be a doctor that performs abortions, and their colleagues associate a doctor approving of abortion. Another example may be volunteers helping in HIV/AIDS hospices and are associated with HIV/AIDS (Phillips & Benoit, 2013).

A structural stigma is a form of stigma that is not caused by face-to-face contact, but rather it is policies or rules that single out those that may have an infectious disease and decrease the opportunities that the person has because they have or had a specific illness or disease (Grappone, 2020). Hatzenbuehler & Link (2014) describes structural stigma as “societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized” (pg. 2), and they provide the example of the Jim Crow laws as a form of stigma. The Jim Crow laws limited a person who was African American to progress through society. Such laws have helped develop a society that believed in segregation and the divide of a person due to their race. As a result, many of the African Americans faced stigma wherever they went in the United States.Another example is in the United States, where gay marriage was illegal until 2015. Those who identified as gay or lesbian would have a tough time expressing themselves in states such as Texas. The expression that many gays or lesbians could show were those that allowed them to come out publicly as gay or lesbian. Other expressions could be showing affection to other gay or lesbian people in the manner that straight people. Until 2015, many had to hide that they were gay or lesbian from the community in order to avoid prosecution. The stigma was not caused by individual beliefs alone, but rather the laws or policies that the government had made.

Health practitioner stigma is the final form of stigma that will be examined. This form of stigma comes from those that should be treating the patient, but rather, the health care practitioner may allow their own bias, prejudice, or discriminatory thoughts to interfere with the job at hand. All healthcare practitioners are usually required to provide the same treatment with the same level of care for everyone, but when one’s personal views interfere with that, people can become stigmatized while seeking help or treatment (Grappone 2020). One example of health practitioner stigma is when a dentist changes ordinary procedures due to HIV/AIDS. There have been instances where dentists will double glove when performing routine procedures or schedule patients with HIV/AIDS (Patel et al., 2014). The stigma here is shown when somebody that has an infectious disease is treated differently. There would have been no reason why there was a need to double glove for a patient for the dentist as it is not within the standard operating procedures.

Stigmatizers

Stigma is usually developed when somebody else targets a person or a group of people because they are different. There are many reasons why people would stigmatize another person. It could be due to their upbringing, social or political beliefs, personal

experience or bias or ignorance and misconceptions of a specific disease. Hall (1976) describes each person's identity as conscious and unconscious. There are qualities that we show that are explicitly learned, within the conscious mind, quickly changed and are considered as objective knowledge, while there are other qualities that are implicitly learned, within our unconscious, difficult to change and considered to be subjective knowledge (Hall, 1976). All aspects of our lives will form different perceptions and explain why a person perceives somebody else or something different. A person's upbringing, religion, personal experience, schooling, access to information and many more social factors contribute to our understanding and perception of others and different situations. This is important when understanding stigma because it is not the person who has the infectious disease that would like to be stigmatized. Rather, it is somebody with a different perception about the infectious disease that will usually stigmatize another person. It is essential to understand the experiences of the victims of stigma and their experiences but also the opinions of the stigmatizer as well as the reasons why they are introducing stigmatizing behaviour towards another person. The people that are stigmatized most likely do not want the attention that accompanies stigma and as such, the experiences that they feel are important to capture since it allows for actions to be taken to support them and provide them with services that may reduce the impact of stigma. On the other hand, understanding the aggressor or stigmatizer allows for actions to be taken in order to address why people have these opinions and misconceptions.The aggressor may perceive the person they are stigmatizing due to personal beliefs mentioned above. These perceptions allow the aggressor/stigmatizer to tell a different experience and by understanding where this experience comes from better response and interventions can be developed to address such issues such as better education or better support systems.

Interventions that could be taken after capturing both experiences could be support groups for the stigmatized people and better public education or better access to factual information for the aggressor. An example of an antagonizing feature about an infectious disease that aids in discrimination and misconceptions is the naming of an infectious disease. Diseases such as the Spanish Flu, The Middle East Respiratory Syndrome, Swine Flu and the last name for HIV/AIDS was the Gay-Related Immune Deficiency. There is a need to understand that when a disease is named after a country or a specific population, it can help develop prejudice and misconceptions about the disease (Krisberg, 2015). The people doing the stigmatizing will have their reasons as to why they have certain beliefs but without engaging in dialogue then it is impossible to properly understand where the perceptions and misconceptions come from.

It may be true that a person takes on dangerous work that puts themselves at a higher risk of getting or contracting an infectious disease, but at the same time, some people see somebody or learn that someone has an infectious disease and actively stigmatizes them because of their infection. The de-stigmatization campaigns are meant to support stigmatized individuals and change the perception of those who would like to stigmatize others.

De-stigmatization campaigns

Stigma has affected people with internal and external issues that separate them from others. Often, the individuals or groups of individuals are cast out or looked down upon by the community. However, such individuals or groups can find a helping hand through de-stigmatization campaigns formed by organizations that target a specific cause or individuals in the community. A de-stigmatization campaign is an act of intervention that may take the form of protesting and advocacy or education (National Academies of Sciences Engineering and Medicine, 2016, pg. 69). The campaigns may raise awareness about a specific issue or educate the public about a particular cause's platform and facts about the infectious disease. In infectious diseases, they help spread the truth about the disease and break misconceptions that people may have about them. Public education and spreading the truth about infectious diseases helps develop an environment where those with an infectious disease can have better mental health. This is a result of the reduction of the stigma that can lead to better physical health and even better opportunities for a better life.

According to the Center on Society and Health from The Virginia Commonwealth University, public education can improve health through income, social and psychological benefits, healthy behaviours, and healthier neighbourhoods (VCU, 2020). Public education is affected by social policies and a person's perception (VCU, 2020). With the correct knowledge about infectious diseases, it can impact the public health and emergency management departments of a country or an organization. Public information affects public health and emergency management because when people understand the risk associated with a disease, they can make better choices, and as a result, the impact of an infectious disease is potentially decreased (VCU, 2020).

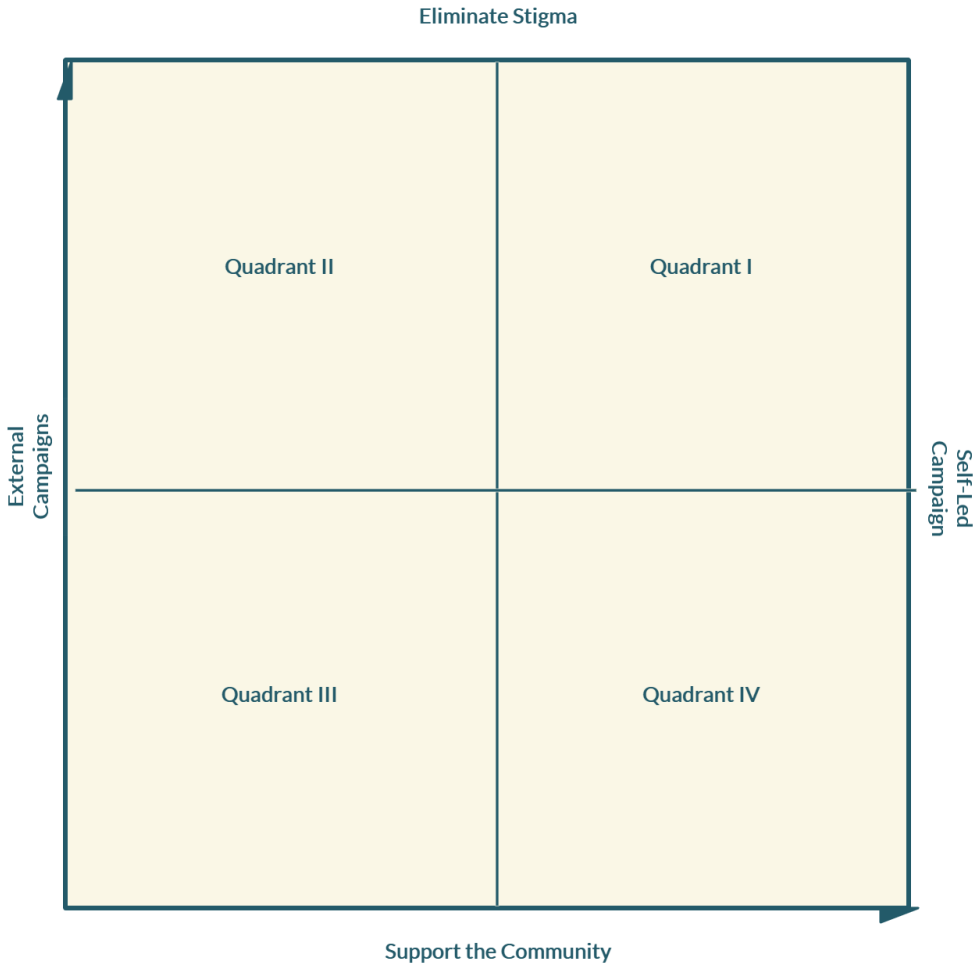
De-stigmatization can be both from an organization or the grassroots level. Charities, Non-Governmental Organizations, Government Organizations, use such campaigns to tackle difficult social issues that affect the overall society. They may come in the form of Public Service Announcements from the government, protests, media or in-person campaigns from Non-Governmental Organizations to convince the government to take action or pass a law. An example of de-stigmatization from an organization is when the Honourable Ginette Petitpas Taylor, Minister of Health, officially endorsed the "Undetectable = Untransmittable" (U=U) campaign 2018. There was a formal ceremony on World AIDS day (Public Health Agency of Canada, 2018). Another example is when an entire magazine was printed using ink laced with HIV positive blood. The point of the campaign was to force "the reader to 'break the seal' to break the stigma since the magazine was sealed in a wrapper" (Bernstein, 2015, para 5). The campaign was supposed to help people realize that HIV blood is infectious only for a short time and that it was safe to contact people with HIV/AIDS.

Grassroots level campaigns and initiatives come from the community. They are led by community leaders, local activists and may spontaneously take form. Grass root level campaigns may use social media, protests and public education to help with de-stigmatization. When Ebola hit the world in 2014, many people from African countries were

stigmatized, and as such, there was one campaign called #IamLiberianNotAVirus. This was a social media hashtag that tried to deter people from stigmatizing people from Ebola-stricken countries such as Liberia, Guinea and Sierra Leone. The campaign "#IamLiberianNotAVirus has spread throughout the online community over the last 24 hours as people have come together to challenge the stigmatization that West Africans are facing as the Ebola crisis continues to grow" (eHospice, 2014).

The de-stigmatizing campaigns can be further broken down into a quadrant chart, as seen in figure 1.

Figure 1. De-stigmatization organization chart



The organizational campaigns and grassroots campaigns can be separate and can be mapped using this grid chart. Government and not-for-profit campaigns may be plotted more towards external campaigns, while local campaigns started by community members may be plotted more towards self-led campaigns. Finally, both can be rated as to whether the campaign or action is meant to eliminate or de-stigmatize the disease or support individuals or groups of individuals with a specific infectious disease. While eliminating stigma can

support the community, the campaigns or initiatives that will be looked for that may be more towards the support community quadrants are those that may provide emotional, mental or physical support for victims of an infectious disease or stigma. Quadrant I will be the top right-hand corner where campaigns are focused on eliminating stigma and are self-led. Quadrant II is in the top left corner, where the campaigns and initiatives are focused on eliminating stigma but from external organizations. Quadrant III is in the bottom left corner, where campaigns and initiatives support the community and are from external organizations. Finally, Quadrant IV is in the bottom right corner where the campaigns and initiatives that support the community are self-led.

The de-stigmatization chart was created to help visualize the different actions that are being done. The x-axis of self-led vs external campaigns were chosen as there were usually two branches of de-stigmatization campaigns. The first came from an organization such as a government body, not-for-profit or a non-governmental organization. In contrast, other campaigns came from the community, such as social media awareness or self-organized campaigns that do not have an organization that supported the de-stigmatization action. The y-axis has eliminated stigma and supports the community because it showed that this was generally where most actions focused their efforts. One group of campaigns or initiatives focused on education and eliminating stigma of individual people while others focused on supporting the community and helping people who were stigmatized. Some campaigns do both where they are educating the public while also providing support to a stigmatized community.

The author created the de-stigmatization chart to help organize different campaigns or initiatives. Each of the points that will be placed on the chart will be subjectively placed based on the author's interpretation and the research that has been done. The points are all relative to each other and, as such, are based on the author's judgment to help the reader visualize what the author is thinking. The points that appear on the chart are the different initiatives being worked on, such as TB clubs, World AIDS Day and public education initiatives. This chart will allow for a visual representation of the different de-stigmatization campaigns explored in the three different infectious diseases. The chart is vital to help map out where different initiatives are and where initiatives should improve on. Finally, it could help summarize the findings of the research being done.

Tuberculosis

The first disease that will be examined is Tuberculosis, also known as TB. The section will begin by looking at TB's historical background and why it is considered an infectious disease. It will then discuss the effects it has on the individual that contracted TB and the rest of society. Finally, the section will examine the link between stigma and TB and the de-stigmatization initiatives that are being done to help those stigmatized for having TB. The background portion of this chapter will allow for added insight as to how stigma may form. It is important to understand the history of tuberculosis as it also provides important information as to when key scientific discoveries were introduced to society. Alongside the background portion is the effects that TB has on the person. It is important to understand these effects as it allows for a connection between the physical illness and the stigma projected upon a person with the disease. For example, the physical impairments that TB can do to a person can hinder the ability to work, and as such, some communities, such as those in Southern Asia, may stigmatize that person or family as they are no longer able to make a living or are unable to provide for the family. Physical, social and economic effects of TB can create situations where stigma can be projected towards a person or group of people.

Background on TB

TB is caused by bacillus Mycobacterium tuberculosis (MT), which spreads from person to person (Zaman, 2010). TB usually affects a person's lungs, but the bacteria can also affect other parts of the body, such as the brain, intestines, kidney and spine (Zaman, 2010; ALA, 2020). TB is not a new disease as the bacteria itself can be traced back to over 70,000 years ago, and it has been infecting humans for over 4000 years (Zaman, 2010). It has affected civilizations ranging from Ancient Egypt to the Middle Ages, and even today in many countries worldwide. Physical evidence of tuberculosis infecting people has been found in Egyptian mummies from 2400 BC, where skeletons were deformed and showed signs of infection. While archaeologists and scientists have found physical evidence in Egyptian mummies' bodies, there is no written record that the Ancient Egyptians knew what Tuberculosis was back then (Barberis et al., 2017). However, there are written records in India that describe TB dating back to 3300 BC and in China, dating to 2300 BC (Barberis et al., 2017, pg. E9).

Other ancient civilizations have described this illness in their records. Ancient Greece, Ancient Rome, and the bible in Deuteronomy and Leviticus describe Tuberculous but with different names. In Ancient Greece, it was known as 'Phtisis.' In the bible, it was named gschachepheth (Barberis et al., 2017). In the Middle Ages, TB was referred to as the "Kings Evil." It was not until the sixteenth century that Girolamo Fracastoro would clearly define what Tuberculosis is, and it would not be until 1679 when Francis Sylvius would describe the exact "pathological and anatomical description of the disease" (Barberis et al., 2017, pg. E10). By 1720, the origins of TB were beginning to be well researched. By March 24th, 1882, Robert Koch was able to isolate the tubercle bacillus and present his findings to the

Society of Physiology in Berlin. After Koch's discovery, there would be numerous vaccines developed, and Koch would be able to contribute to the "elucidation of the infectious etiology of TB" (Barberis et al., 2017, pg. E11). In 1905, he would be awarded the Nobel Prize in Medicine (Barberis et al., 2017). The progress of the discovery and identification of Tuberculosis led to the development of treatments and vaccines throughout history.

The origins of TB are important to understand stigma because it shows that TB has been around for a long time, and it may also help to explain why the de-stigmatization campaigns only began to appear after 1905. As stated above, it is not until Koch discovers the specific bacteria that causes TB that a vaccine is developed and implemented. As such, the origins of where TB came from and its existence is important when first trying to understand the disease and why people are stigmatized. Many of the perceptions that we have today about diseases could have been passed down from different parts of history, and the knowledge required to understand the infectious disease may not be there, which results in the stigmatization of those that contract it. In some instances when a disease is discovered to be caused by something else and is not solely caused by the person themselves then a new perception can be created where the blame is shifted from the person to the cause. For example, the cause of TB is due to bacteria and not because a person is being punished or because they are a lower class.

Effects of TB

TB is an infectious disease because the bacteria that causes TB is spread through different environments from person to person. Once a person has inhaled the bacteria, it will attach itself to the person's lung tissue (ALA, 2020). TB can only develop over continuous exposure to the bacteria, usually by continuously spending time with somebody that has TB. There are four main types of TB: pulmonary, extra pulmonary, multidrug-resistant and latent. According to the National Health Service (2020), latent TB occurs when the bacteria are present, but the symptoms are not active. Pulmonary and extra pulmonary TB is where the bacteria affect the lungs or outside of the lungs, respectively. Finally, multidrug-resistant TB is where the contracted TB strain does not respond to the antibiotics prescribed. Usually, antibiotics, steroids, or chemotherapy are used to treat TB. These treatments can still be hard to find in less developed nations, so stigma may be attributed to TB since TB's effects and knowledge are not widely known.

Physical effects

According to the National Health Service (2020), if TB is not treated, it can cause death (NHS, 2020). If the antibiotics are not taken to the full course, "the TB infection may become resistant to the antibiotics, which is potentially serious because it can be difficult to treat and will require a longer course of treatment with different, and possibly more toxic, therapies" (NHS, 2020). If treatment is taken for the full six months with all four TB drugs, patients can make a full recovery (WHO, 2020). Some symptoms associated with TB are coughing, fever, chest pain, blood in sputum, breathlessness, weight loss, and weakness

(Weiss et al., 2008). In 2018, the WHO (2020) reported that a total of 1.5 million people, of which 205,000 were children, died from TB and 10 million people, of which 1.1 million were children, fell ill with tuberculosis. TB is severe enough that it was the first infectious disease that was declared a global health emergency (Zarman, 2010). Developing and transitional countries are usually areas that are impacted by TB.

If TB is left untreated, it may kill the person, but it may also mutate and become drug-resistant, which means that if it spreads to others, it becomes harder to treat and uses more resources. Drug-Resistant TB is harder to treat and instead of antibiotics, chemotherapy and other toxic drugs are used, which may take up to two years before somebody is cured (WHO, 2020). In 2019 "A global total of 206 030 people with multidrug- or rifampicin-resistant TB (MDR/RR-TB) which is a 10% increase from 186,883 in 2018(WHO, 2020). The stigma cast upon these people also perpetuates the disease's growth since it makes people not address the issue when it is latent or still easily curable. It also allows areas of lower socio-economic status or people living in poverty to stay in the same state since the resources they have access to must take on the burden of more visits and more resources to treat drug-resistant tuberculosis.

Economic Effects

The physical effects of Tuberculosis can devastate the body of an individual and can also devastate a family. The devastation of TB is increased due to the "economic decline, insufficient application of control measures, and the HIV/AIDS epidemic. (Ahlburg, 2000, pg. 6). In developing countries, it is a continuous cycle of poverty and illness. The economic situation is already poor, which does not allow people to access the necessary resources to keep healthy. This then leads TB to spread and increases citizens' economic loss since they are unable to work. In particular, the effects of the loss are compounded when a woman is infected or killed by TB. The household will first lose money gained by her earnings and be affected by the loss of the activities she would routinely perform in the home (Ahlburg, 2000, pg. 9).

Furthermore, in developing countries that cannot receive or obtain the drugs or procedures necessary to treat TB at a low cost, families that have a member with TB face even more difficulty financially when trying to receive treatment for TB as the treatment adds cost to an already thin budget. In countries such as Bangladesh, India or Thailand, loans, money transferred, and debt is all a part of the picture for affording treatment (Ahlburg, 2000). In Uganda, there is a record of children being pulled out of school to help cover treatment costs. The school fees may help temporarily, but its effects on the child may be more long-term (Ahlburg, 2000). The family and individual can face both financial and physical hardships when someone has contracted TB.

Social Effects

Another impact a family may face is psychological and social. Such an effect can be a result of stigma. Psychological effects affect the psychological state of the individual or family's psychological state, including depression, a deterioration of mental health, self-isolation and self-doubt. Social impacts are those that affect the person in regard to the connection between the community and themselves.

The public stigma that many people face can lead to self-stigma, label avoidance, perceived stigma and stigma by association. The negative behaviour that is projected upon those with TB can lead to depression and lower life satisfaction. The patient that has TB often socially isolates themselves and channels it internally. This leads to label avoidance since many may not seek treatment or seek help sooner since they want to avoid being stuck as someone that has or had TB. This leads to adverse effects for the individual and the rest of the community (Baral 2007, pg. 3).

The effects of TB on a person, whether it is physical, social or economic, play a large role in the stigma of TB. Stigma may come from a person displaying the symptoms of TB such as coughing, fever or weight loss, which may lead to the family or individual suffering from economic impacts such as a loss of job. Ultimately social impacts where people identify those that are infected as a 'lower' class of people because they are disease-ridden. The physical and economic effects of TB perpetuate stigma as the physical display of TB can result in the society or community involuntarily isolating that person.

Stigma and TB

The stigmatization of TB around the world has a significant impact on the people that have TB and recover from it. That is why many, as stated before, may choose to hide their diagnosis or may even delay receiving treatment. Tuberculosis creates several types of stigma for the patients that urgently need care. These types of stigma will be explored using the categorization method outlined in the background section.

Public Stigma

The first type of stigma is public stigma. Public stigma is seen less in developed countries where public education is available, and access to information is more open than those where information is unavailable or limited. There is a better understanding of how Tuberculosis is transmitted in such countries. However, in countries or even communities unable to access the information, there is a greater chance that members with TB are stigmatized (Courtright & Turner, 2010). When one is diagnosed with TB and the public discovers it, this can have very disastrous effects on the person's life and family members' lives. Many people diagnosed with TB may face stigma and discrimination from the community, accompanied by anxiety, depression, lower life satisfaction, unemployment and lower income (Ahlburg, 2000; Weis et al., 2008). In some countries, "Family and friends may reject TB patients, they may receive less social support during treatment, or they may lose

their jobs" (Ahlburg, 2000, pg. 16). They may lose their job because they are seen as 'damaged' in some cultures, and as such, they become unable to find an employer willing to hire them (Ahlburg, 2000).

While public TB stigma can affect both males and females, there is a more significant impact on women in most, if not all, countries. Women may face an impact on their marital status or even family rejection. In many parts of the world, the perception of Tuberculosis can vary. A study conducted by Somma et al. (2008) found that female patients in Bangladesh have significantly higher stigma indexes, while in India, the male and female difference was not significant. Somma et al. (2008) conducted a semi-structured explanatory model interview with over 100 participants. The study was used to assess different categories such as distress, perceived causes and seeking help. They were also looking at indicators of self-stigma of both men and women. The conclusion they found was that "Stigma both influences and indicates the effectiveness of TB control. Cultural epidemiological methods clarify cross-cutting and local features of stigma and gender for TB control" (Somma et al., 2008, pg.856). Somma et al. (2008) further reports that in the South Asian sites, many women had low self-esteem and concern about social isolation due to the insolation received from the community since they had TB. Somma et al. (2008) explains that associations with HIV/AIDS were linked to TB stigma in Malawi with a gendered lens, where sexual contact is a perceived cause "more associated with stigma for men and less for women" (pg. 856). Those that have contracted TB are often associated with negative stereotypes such as being poor or having a bad history. Furthermore, TB can destroy economic and social status since the public may see them as diseased. In the South Asian countries above, it is hazardous for families and women, especially since a TB diagnosis can obliterate any marriage opportunities or any social advancement as other perceived associations of TB are "malnutrition, poverty, being foreign-born, and low social class" (Courtwright & Turner, 2010, pg. 36).

While in developing countries or low to middle-income countries, the stigma associated with TB can be detrimental to a person. This is also the case in developed countries where TB stigma can exist with the same perceptions and discriminations seen in developing nations. Craig et al. (2017) found that in countries such as Canada, the United States of America, New Zealand, Norway, and Sweden, all had community members report that stigma was an issue. In New Zealand and Norway, the cases count is minimal, with about 300 cases per year, and in Sweden, it was about 530 cases in 2017(Ministry of Health NZ, 2020; Norwegian Institute of Public Health, 2016; Jonsson, 2016). In the United States, 8,916 cases of TB are reported, but up to 13 million people have latent TB (CDC 2020). Many developed countries have cases coming from groups "defined as hard-to-reach, or underserved, and are characterized by complex health and social risks, such as homelessness, imprisonment, HIV, substance and alcohol misuse and lack of entitlement to welfare" (Craig et al., 2017, pg. 90). Craig et al.'s study was a systematic review of literature used to identify research and any gaps in the knowledge (2017). The study limited the articles that were being looked at to January 1, 2006, and August 1, 2016, and the articles were included if they are from low incidence countries. It is evident that in developed and developing countries, those that contract TB are also stigmatized and are often associated with unwanted traits. This is

because a person can be associated with another disease such as AIDS or can be deemed undesirable in the case of women looking to get married. The poor are often associated with TB in both developed and developing countries as they cannot receive treatment and will usually have a high risk of infection.

Self-Stigma

Self-stigma in TB is a common side effect of public stigma. As Ahlburg (2000) mentions, many times, the patients discovered to have TB will have stigma from the public, but this public stigma is followed by anxiety, depression, and lower life satisfaction, which is all reinforced by unemployment and a lower income. The self-stigma inflicted upon oneself is seen when they start to believe that what is being said about them and TB is true. This is where the mental effects appear and can cause the TB patient stress.

Perceived Stigma

Another form of stigma that is found with TB patients is perceived stigma. While TB is a disease that can be contracted by itself and does not need to be a result of a coinfection, it has been found that many TB patients are automatically associated with HIV/AIDS, which may lead to social isolation (Ahlburg 2000). HIV/AIDS is closely associated with TB since HIV/AIDS can contract TB easier since the weakened immune system cannot protect the body against the bacteria. The association between HIV/AIDS and TB in low and middle-income countries is derived from poor living conditions and high infection rates. Even in developed countries, many associate TB with the country's poor.

The perceived stigma continued when Hatherlall et al. (2019) continued Somma's findings in Bangladesh, Nepal, Pakistan, India and Columbia. It was reported that TB also affected marriage since there was the perception of "If someone hears that an unmarried girl has TB, there would be a problem with her marriage. Who will marry a diseased girl?" (Hatherall et al., 2019, pg. 1112). An unmarried Nepalese man reported to the study that "society is harder on women not only if they have any disease, but also if they do not or are not able to work hard. The impact of TB on a person's ability to work, and in particular on a woman's ability to work, may be as much of an issue as TB itself (Hatherall et al., 2019, pg. 1112). This perception of women and the population that has TB significantly affects their economic status and social status. In Hatherall et al.'s research the data collected points out that the stigma is gendered towards females and that the males do not see as much stigma in this sense. Hatherall et al.'s (2019) study was based on a grounded theory approach. The researchers first had a three-day workshop before beginning with interviews of health care workers and people with TB in different sites across Bangladesh, Nepal and Pakistan. There were 73 individuals interviewed, and each interview was between 45-60 minutes. The study's objective was to further the understanding of the disruptiveness of stigma in people's lives, especially the negative impact that TB has on marriage prospects (Hatherall et al., 2019). In countries such as Pakistan, Nepal and Bangladesh, being a woman and having TB causes many social issues. In particular, it can cause problems if they are a housewife, a mother or a bride-to-be. Hatherall et al. (2019) describe these three situations where TB may damage the

housewife's reputation since she may be too weak to work. It damages the image of being a mother since TB can affect the viability of a pregnancy, and finally, it damages the appearance of a bride or potential bride since "nowadays everyone wants a daughter-in-law who earns money" (Hatherall et al., 2019, pg. 1113). The study that Hatherall et al.'s (2019) and Somma et al.'s (2008) study both demonstrate that stigma is gendered towards females and that females are more likely to experience stigma. However, it is still possible for males to experience stigma but not as much as females do in the countries that were explored by both studies.

Label Avoidance

The next form of stigma that TB has is label avoidance. Many people who have TB also do not seek treatment since the local hospital or clinic may have somebody they know. In Pakistan, a health worker commented by saying, "if the health worker knows, then everybody will come to know about this" (Hatherall et al., 2019, pg. 1115). The health worker commented that there have been records of health workers divulging patient information to family members or members of the community (Hatherall et al., 2019). In rural villages where everyone knows each other, the information can spread quickly, and soon the patient is exposed to stigma (Hatherall et al., 2019). In this example, label avoidance is a way to avoid public stigma. It is detrimental to a person with stigma to do this because it can cause a treatable form of TB to progress and become drug-resistant, leading to death.

Table 2. TB Stigma Summary

	Where Stigma Occurs	**Stigmatizer**	**Who is Stigmatized**	**Consequences**
Public Stigma	In the general community of villages and cities. Public stigma due to TB can be found anywhere.	The general public, family members, co-workers	Men and women that have contracted TB.	Marriage proposals are destroyed, family rejection, social and economic status destroyed
Self-Stigma	Internally	A person with TB	Men and women that have contracted TB.	People with TB can begin to feel anxiety, depression, lower life satisfaction
Perceived Stigma	In the general community of villages and cities.	The general public, family members, co-workers	Men and women that have contracted TB.	An automatic association with HIV/AIDS for some patients, women are deemed no longer viable for motherhood.

Label Avoidance	In the general community of villages and cities. As well as treatment centres, medical facilities, doctor's offices, etc.	The general public, family members, co-workers	Men and women that have contracted TB.	TB patients do not take the necessary medication to eradicate all the bacteria that caused the original TB, and as a result, the TB re-emerges but is not drug-resistant.

De-stigmatization campaigns

De-stigmatization campaigns and actions from all levels of society have been trying to raise awareness about the prevention measures that can help reduce infection. As well as education the public about how stigma towards people who have an infectious disease can harm that person and the social cohesion of the community. These campaigns and actions serve as a way for health agencies and governments or even passionate people to educate the public of a specific disease or health measure.

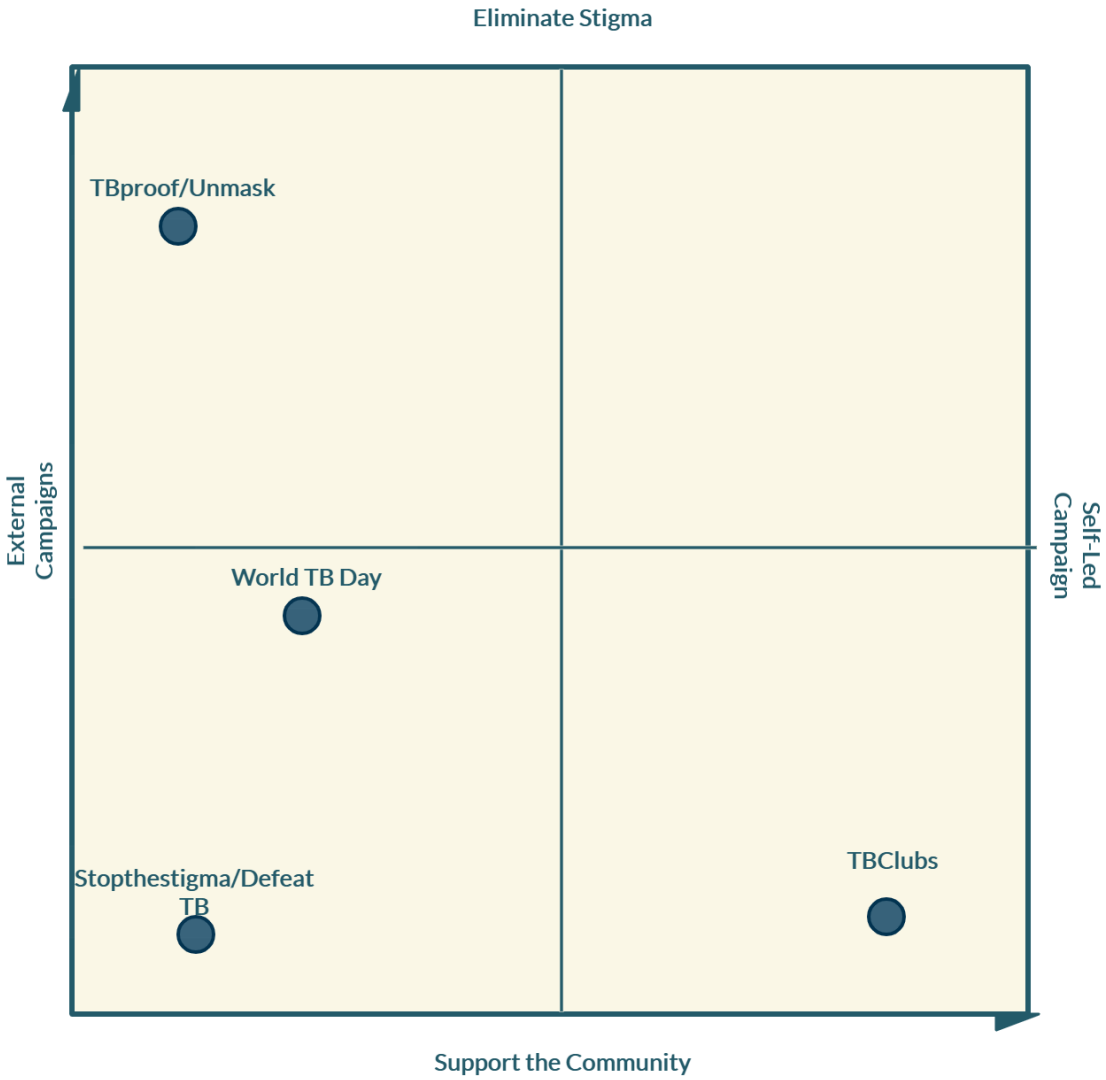
While many people are stigmatized due to a TB diagnosis, there are, and there have been campaigns and members of organizations and the general public fighting to break the cycle of stigma and poverty. There have been de-stigmatization actions that have tried to create awareness and debunking myths about TB. The de-stigmatizing campaigns that are happening range from academic studies and global initiatives from major organizations to actions done at the local level. These actions also offer a way to support TB survivors to overcome stigma and isolation. Courtright and Turner (2010) have discussed several ways to help the de-stigmatization process in their article. Courtright and Turner's research was done through a literature review of articles that had keywords such as tuberculosis, stigma, and stigmatization. They identified 168 articles, of which 159 were from PubMed and nine from the reference section of articles found (Courtright and Turner, 2010). Of the 168 articles, 69 were rejected, and with the remaining articles, they summarized the interventions and ways that TB stigma could be characterized, measured, and combated (Courtright and Turner, 2010). They find that support groups in Africa or TB clubs can help "to offer social support, arrange transportation to clinics, encourage treatment adherence, monitor for treatment side effects. and encourage TB screening among at-risk community members" (Courtright & Turner, 2010, pg. 38).

TB clubs are support groups that help people that have or had TB overcome stigma and provide a supportive community for those in need. A TB club's main focus is ensuring that patients adhere to treatment and is usually organized by a TB Health Care Professional (Demissie et al., 2003). However, "the regular meetings were for members of the TB club to support each other in adhering to treatment, and to share information about the course of the disease and possible drug side effects." (Demissie et al., 2003, pg. 2012). Demissie et al.

(2003) began this idea when she did work on TB clubs in North Ethiopia where she found "44 out of 64 patients completed TB treatment while only 30 of 64 completed treatment in the comparison group" (pg. 2009). The same study also found that those that in the TB club had "remarkable changes to the initial reactions to a TB diagnosis, misconceptions as to the cause and treatment of TB, the social isolation and compliance and belief in the modern health care in the TB club area" (Demissie et al., 2003, pg. 2009). TB Clubs are related to stigma as these clubs provide a support group for those that face TB Stigma. It is a gathering of people experiencing similar conditions, and it provides support for TB patients suffering from stigma. It is a place to feel safe and receives encouragement to complete treatment.

TB clubs would fall in Quadrant 4, as seen in Figure 1.1, the De-stigmatization chart for TB. The TB clubs are designed to support TB patients and survivors by navigating reality and providing support when stigma is being projected upon them. TB clubs are not organized by an organization but rather by a healthcare professional or other members to encourage the sharing of facts and make sure people are adhering to drug treatments.

Figure 1.1. De-Stigmatization chart for TB



Other forms of de-stigmatization are from local groups that have grown to an international stage. For example, the organization TBproof aims to "be a diverse TB advocacy organization that provides platforms where TB-affected communities can contribute to improving TB prevention and quality of care." (TBproof, 2020). TBproof's principle activities are to reduce TB risk for health care workers, their unmask campaign, contributing to the address of TB as a global health emergency and bringing hope to TB communities (TBproof, 2020). They are providing advocacy for control measures and advocating for treatment as prevention for TB. Their efforts have been successful through various events, social media campaigns and participation in global affairs. TBproof reported in their 2018 report that throughout 2018 they had reached over 9000 people on social media. The organization may only be getting a small fraction of the population, but it is still developing connections, and it is doing its part to de-stigmatize TB.

One of their aims is to raise awareness about TB, and this is done through their unmask stigma campaign. Unmask is “an international awareness and education campaign, aimed to expose the true character and the stigma surrounding tuberculosis” (TBproof, 2020). Unmask uses the concept of putting on a mask to help prevent the spread of TB, and during World TB Day, they have the challenge to encourage people to wear masks to raise awareness that wearing a mask prevents the spread of TB. The campaign is supposed to normalize the wearing of masks as prevention, as the point is supposed to raise awareness that" anybody can get TB and everybody needs support” (Unmaskstigma, 2020). Unmask measures their success through the number of people they reach on social media and their campaigns. They are currently the largest advocacy group in South Africa for TB. (Unmaskstigma, 2020). The Unmask Campaign looks to social media for people to post pictures of themselves wearing a mask and using the hashtag #UnmaskStigma (Unmaskstigma, 2020).

TBproof and their campaign Unmask would be in Quadrant 2. This is shown in Figure 1.1, the De-stigmatization chart for TB. The campaign aims to eliminate stigma for those wearing masks and is also organized by a non-for-profit organization. There is some aspect of supporting the community through other initiatives, such as providing supplies that helps support the community. While TBproof is not a direct action or organization that only deals with stigma for TB, one of its campaigns, Unmask, does target stigma directly as it creates awareness that wearing a mask helps prevent the spread of TB, and it de-stigmatizes the usage of a mask by those that have TB. The Unmask campaign de-stigmatizes an aspect of TB as it also raises awareness about mask-wearing and masks usage, which is an important part of prevention and the reduction of the spread of TB.

A global campaign that aims to educate people about TB is World TB Day, which many health organizations such as the Centre for Disease Control and Prevention and the World Health Organization use to promote TB awareness and education to the public. This global event that happens on March 24th (WHO, 2020) and “aims to raise public awareness about the devastating health, social and economic consequences of TB, and to step up efforts to end the global TB epidemic” (WHO, 2020). World TB Day was first established in 1982 by the International Union Against Tuberculosis and Lung Disease (International Union Against Tuberculosis and Lung Disease, 2002). March 24th was chosen for World TB Day as it is the day that Robert Koch discovered the bacteria that causes Tuberculosis (CDC, 2016). This day is not supposed to be a celebration but rather a day to raise awareness, educate on the devastating effects of TB, and prevent and control TB (CDC, 2016). World TB day usually has a theme that has been attached to it, and in 2020, the theme was ‘IT’S TIME’ (Tiberi et al., 2020). This year, World TB day focused on obtaining the goals set out in 2018, which were “to: scale up access to prevention and treatment; build multi-sectoral accountability; ensure sufficient and sustainable financing including research; promote an end to stigma and discrimination, and promote an equitable, rights-based and people-centred TB response” (Tiberi et al., 2020, pg. S1). It is also important to note that World TB day allows for reflection and examination of how far the world has progressed towards the 2035 goal of reducing mortality and incidents by 90%-95% (Tiberi et al., 2020).

World TB Day would fall under Quadrant 3 since the UN and other organizations support it, and the day aims to raise awareness to support the community. However, this day also allows for awareness building towards ending stigma so the location will be closer to the x-axis, as seen in Figure 1.1, the De-stigmatization chart for TB. While World TB Day has been used to raise awareness about the stigma surrounding TB, many campaigns associated with World TB Day take the form of addressing the shortage of medical supplies for health care professions or discriminating and prejudicial behaviours. It is important to note that while some campaigns are used to help with de-stigmatization, many of the actions associated with World TB Day relate to other issues surrounding TB. World TB Day allows for education about the stigma surrounding TB, but that is only a fraction of the actions done during this specific day.

The Heartland National TB Center at the University of Texas ran a campaign called "Stopthestigma " which tries to change the way we think and speak about TB. In Uganda, the University Research Co. has been running the campaign "Defeat TB," which promotes education and establishes partnerships with all local community areas to raise awareness about TB. Other movements are extensions of actions that aim to eradicate TB. For example, on no discrimination day, the Stop TB partnership launched a campaign to educate people and reduce the stigma of having TB or HIV/AIDS. The campaigns Stopthestigma and Defeat TB would be in Quadrant 3 as they are organized by an organization, and they are used to support the community as they develop education and partnerships with the local community. This is shown in Figure 1.1, the De-stigmatization chart for TB.

Many of these campaigns or actions are considered 'recent' as compared to the long history of TB. An explanation of this phenomenon is that the history of TB has covered or has been present since the beginning of early civilizations, but the discovery of what caused it did not occur until the 1860s, and many medical actions would not take place until the 1920s -1940s (CPHA, 2020). It is also important to recognize that TB is not a disease that has been publicized that often. In many cases, charities, celebrities and non-for-profits tend to concentrate on diseases that capture an audience and can raise money. TB is an issue that many see as one that is solvable or avoidable, and as such, the attention is turned towards other diseases such as cancer or HIV/AIDS. Throughout the research conducted to gather information, most if not all campaigns and scholarly articles have only mentioned the usage of 'modern' campaigns or actions to destigmatize TB, and in early periods of human history, most people were often stigmatized and made an outcast of society.

One issue of note about the de-stigmatization campaigns is that the academic realm has not conducted enough research to reduce TB stigma. Courtright & Turner (2010) notes that "relatively few interventions have been introduced to reduce TB stigma, and few investigators have measured whether reductions in TB stigma decrease diagnostic delay or improve treatment compliance" (pg. 38). There are very few studies that have been published that show the effectiveness of such campaigns. While there have been many suggestions that education and support programs may help reduce stigma with individuals that have TB, Rajeswari et al.'s (2005) article suggests that there is a need for "social support needs to be

strengthened" (pg.1852). The article continues to elaborate that social support should look at the needs of women and those who cannot resume work due to the physical disability resulting from TB. Other forms of support at family counselling and active outreach to "detect and capture cases early on" (Rajeswari et al., 2005, pg. 1852)

Future Interventions for De-stigmatization

The actions needed to break TB stigma can be seen as a combination of educational and awareness bringing. But as Rajeswari et al. (2005) have pointed out, it is not enough to simply educate the public about TB and the stigma that comes with it. Further action is needed to disrupt the cycle that some people have lived through for quite some time. There must be actions that will help improve TB survivors' social aspect and those associated with them. The focus of de-stigmatization is usually about one instance of stigma and the stigma that may follow until the eradication of TB. The focus of stigma is important but supporting the survivors' social development during and after TB is also important. Courtright & Turner (2010) suggests that the TB clubs which provide social support to survivors and their families should be better developed, and Rajeswari's paper also supports this notion. Also, further research with a standardized measurement tool to track changes and to "assess whether a reduction in TB stigma leads to improved time to TB diagnosis, treatment compliance, and, ultimately, reduced TB morbidity and mortality" (pg. 40) should be developed.

As TB is a growing problem in today's world, the need for more interventions in specific communities with at-risk populations is a growing need if stigma and TB are to be controlled. At the same time, more research is needed to formally conclude what interventions are working and which ones need to be altered. It may become useful to examine other infectious diseases that have led to an individual's stigma or a group of people to understand what methods effectively tackle TB stigma. Courtright & Turner (2010) suggest that it would "be useful to assess whether interventions are known to reduce HIV/AIDS stigma have any effect on TB diagnosis and treatment" (pg. 40). The idea to use other diseases as starting points is also supported by Daftary et al. (2017), which states that the TB community has not been able to "adequately contest programmatic norms that reinforce TB stigma" (pg. 1). A major difference between the HIV/AIDS grassroots campaigns and the TB campaigns is that HIV has been able to "successfully rallied forces to challenge the stigmatization of people with HIV, through collective, grassroots human rights movements that have led to tangible shifts in policy" (Daftary et al., 2017, pg.1). The solution which is suggested by Daftary et al. (2017) is similar to what Courtright & Turner (2007) suggest with TB clubs. There needs to be "consciousness-raising, a form of activism where people with and affected by TB come together to share their experiences, identify common struggles and begin collectively organizing to change harmful practices" (Daftary et al., 2017, pg.1).

Other methods that have been suggested which may help with the de-stigmatization of TB would be to "shift from a strictly biological to a multidisciplinary understanding and collaboration in seeking the successful control of "ordinary," i.e., drug-susceptible,

tuberculosis" (Aguilar Jr., 2009, pg.303). Aguilar Jr. (2009) suggests that public health campaigns may have created the stigma in the first place. He continues this idea by stating that medical practitioners today" influenced by the stigmatization of this disease, often unwittingly make the control of tuberculosis ineffective (Aguilar Jr., 2009, pg. 303) since they may not wish to offend and may use a different term to describe the tuberculosis diagnosis. With health care professionals not wanting to offend or cause an issue with the family or the patient, it causes epidemiological implications, and as such, the control of TB is lost since it allows the disease to grow.

Another factor that shows the need to have a multidisciplinary understanding of controlling TB is the history from which TB stigma originates. While TB used to be incurable and once a person contracted tuberculosis would die, there is a cure today. In Pakistan, "uncertainties about the fact that TB is curable prevail widely and contribute to the social stigmatization of TB patients" (Liefooghe et al., 1995, pg. 1691), which also shows that education about the cure is also necessary to decrease stigma in TB. Patients with TB should live their lives naturally and not be subjected to stigma or discrimination because of a medical illness that is curable and as such future education programs should encourage the message that TB is a disease that is curable and should address "issues in popular health culture" (Aguilar Jr., 2009, pg. 303).

The de-stigmatization campaigns that are currently happening are a good beginning for the fight against TB stigma. However, the campaigns must go deeper and further when it comes to influencing the public about stigma. One major solution suggested by numerous authors and researchers is the targeting of the norms and values that people hold about TB. Courtright & Turner (2007), Daftery et al. (2017), Leifooghe et al. (1995) and Aguilar Jr. (2009) all suggest that the norms must be addressed in a holistic manner where it is not just grassroots and organizations leading education campaigns. It will be addressed further in length in the HIV/AIDS where the social support structures are provided, and the community can rally behind those who have TB. More people also need to be educated that TB is curable, and the survivors must be able to speak out and tell their story because they can physically demonstrate that TB can be overcome and that the popular opinion that the public has is false. To overcome TB is to change the people's mindset that project stigma, which is not done in one moment. It will be done over a long period, even one or two generations.

HIV/AIDS

The next section will be examined is HIV/AIDS or Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome. This section will begin with a historical background to give insight into where HIV/AIDS came from and then move on to the effects of HIV/AIDS to show how it affects the human body and how there might be stigma attached to people living with HIV/AIDS (PLWA). After, the section will explore the de-stigmatization campaigns used by people from the community and organizations to support the community or eliminate stigma. The section will explore creative ideas like printing a magazine with HIV positive blood in ink or how celebrities such as Princess Diana helped de-stigmatize HIV/AIDS at a point in time where PLWA were highly stigmatized. Finally, the future of de-stigmatization will be explored by looking at the suggestions that may have been made to improve the current campaigns and initiatives. The background also offers insights as to how stigma may form. For example, people of African descent are often associated with HIV/AIDS due to its origins. After the chapter will continue with the effects of the disease, they also contribute to the stigma that people are subject to by others. Physical symptoms can cause people to have prejudice and discrimination towards those who show HIV/AIDS symptoms, leading to stigma. The economic effects can also produce circumstances where people are subject to stigma due to the level of care they have access to.

Background on HIV/AIDS

The Human Immunodeficiency Virus infection of HIV is a disease that came from "the result of multiple cross-species transmissions of simian immunodeficiency viruses (SIVs) naturally infecting African primates" (Sharp & Hahn, 2011, pg. 1). HIV has two categories, type-1 and type-2 or HIV-1 and HIV-2 (Sharp & Hahn, 2011). HIV/AIDS is caused by HIV-1-M, derived from the SIVcpz found in Chimpanzees in Southeastern Cameroon (Sharp & Hahn, 2011, pg.1). The SIVcpz was created when chimpanzees hunted and ate two smaller monkey species infected with a different strain of SIV (AVERT 2019). After the chimpanzees ate the smaller monkeys, the SIV were joined together to form SIVcpz, which is the cause of HIV (AVERT, 2019). SIVcpz supposedly transferred to humans when the chimpanzees were hunted and eaten, or the chimpanzee's blood entered a wound that allowed the SIVcpz to move to a human body (Avert 2019). Most times, the human body protected itself from SIVcpz but eventually, it evolved and survived in the human body, thus creating HIV-1(Avent, 2019). HIV-1 is not just a single strain of virus but rather a virus that has four groups. They are named M, N, O, P, which results from independent cross-species transmission (Sharp & Hahn, 2011). Group M currently is the virus group that has created the pandemic, while groups N, O and P are rare and have limited case numbers (Sharp & Hahn, 2011). Due to Group M, the World Health Organization (2020) estimated that 38.0 million people live with HIV at the end of 2019, of which 1.7 million cases were discovered in 2019. The World Health Organization (2020) also estimates that HIV has killed 33 million people.

The second strain of HIV, HIV-2, was discovered in 1986. HIV-2 is derived from the SIVsmm virus found in monkeys. This is a difference between HIV-1 and HIV-2 since one comes from chimpanzees and the other from monkeys. HIV-2 is mostly found in West Africa, and case numbers of HIV-2 have been declining (Sharp & Hahn, 2011). While the number of cases is falling, the overall number of HIV cases is still at the same level since HIV-1 is taking over the HIV-2 cases.

The first case of HIV verified was in 1959 from a man living in the Democratic Republic of Congo, which was also the first time scientists had confirmed HIV infection using a blood sample (Avert, 2020). While the first verified case was in 1959, scientists and researchers concluded that the first transmission of SIV to HIV in humans was around 1920 in the Democratic Republic of Congo, specifically in Kinshasa (Avert, 2019). The high population of migrants caused the spread of HIV in the Congo, compounded by the sex trade that was developing in the area (Avert, 2019). By 1937, HIV had spread to 120 kilometres west of Kinshasa to Brazzaville, and by 1980, all HIV infections in the Democratic Republic of Congo were outside of the Kinshasa area (Avert, 2019). While HIV was spreading in the Congo, it also travelled to Haiti by the 1960s as it was brought back from workers in the Democratic Republic of Congo, and by the 1980s, the United States of America was seeing an increase in HIV awareness. In September of 1982, AIDS was given its name (CDC, 1982), and in 1983 HIV was discovered to be the cause of AIDS by Françoise Barré-Sinoussi and Luc Montagnier from the Pasteur Institute in Paris' (Abbott & Brumfiel, 2008). It was first called lymphadenopathy-associated Virus (or LAV) by the French researchers, but in the United States, they also made the same discovery around the same time and called it HTLV-III(Avert, 2020). There was a dispute of who discovered the cause and who should be credited, but the incident was resolved when the Nobel Committee awarded the Nobel Prize in Physiology or Medicine to Françoise Barré-Sinoussi, Luc Montagnier and Harald zur Hausen (Abbott & Brumfiel, 2008).

This background portion of HIV/AIDS is important because it identifies where HIV/AIDS originates from, which exposes where society has a misconception that many African Americans or those that come from Haiti or Africa have HIV/AIDS. This is vital to understanding stigma because this is a point that can be addressed when trying to educate people, and it also provides researchers with a point of understanding of where the misconceptions come from. The second portion of this section, where it describes the naming of HIV/AIDS by the United States and France, is important because providing an official name scientifically supported rejects any discriminatory names such as “Gay man’s disease.” It is also important to understand where the name came from to ensure that it is used correctly. Also, officially recognizing this infectious disease's naming will also legitimize the de-stigmatization actions and initiatives that others take as a reputable institution accredits it.

Effects of AIDS/HIV

HIV is classified as an infectious disease due to its ability to “target the immune system and [weaken] people's defence against many infections and some types of cancer

(WHO, 2020, n.p.). Furthermore, the virus can destroy or disrupt immune cells' function in the individuals infected, which causes immunodeficiency (WHO, 2020). With a lowered immunodeficiency, the infected person is more susceptible to infections and diseases (HIV.gov, 2020), making a person more vulnerable to other infections and diseases. HIV/AIDS is spread mostly through bodily fluids from a person with HIV/AIDS during unprotected sex or through sharing equipment used for injections (HIV.gov, 2020). As of today, HIV/AIDS is an incurable disease, but many people can delay the effects of HIV/AIDS through Antiviral Therapy (CDC, 2020). The only way to know if one has HIV/AIDS is through blood tests (CDC, 2020).

Physical Effects

There are three stages of the HIV/AIDS process. The first stage is an acute HIV infection, the second is a chronic HIV infection, and the final stage is Acquired Immunodeficiency Syndrome or AIDS. The symptoms of HIV may vary between people. Some people may have flu-like symptoms for two to four weeks after being infected, called acute HIV infection (CDC, 2020). The symptoms include fever, chills, rash, night sweats, muscle aches, sore throat, fatigue, swollen lymph nodes and mouth ulcers (CDC, 2020). However, some people may not feel sick during stage one. In stage two, HIV is produced at very low levels, but people can transmit HIV (CDC, 2020). As well, some people may not show any symptoms of HIV, while others may show symptoms and progress faster (CDC, 2020). From stage two to stage three, the HIV in the blood "goes up, and the CD4 cell count goes down" (CDC, 2020, para 3). After this happens, they move on to stage three. In stage three, HIV infection is the most severe, and HIV has caused AIDS, which damages the immune system to the extent that other severe illnesses begin to arise (CDC, 2020). Without any treatment, a person with AIDS usually has three years to live, while those that can get testing and begin the medication early may live a full and extensive life (CDC, 2020).

Economic Effects

While HIV/AIDS's physical effects can be deadly to a person, there are also economic effects that are felt on various levels worldwide. First, HIV/AIDS and other major infectious diseases affect global economies since it "reduces the stock of human and physical capital" (Bonnel, 2000, pg. 3). Human capital is important since it is the number of people who have the skills and knowledge to produce materials, while physical capital is the products that are made by people (Huff, 2018). HIV/AIDS usually affects a person while they are in their most productive, and as a result, the workforce and economic development may be affected (Bonnel, 2000; Gayle & Hill, 2001). Dixon, McDonald, and Roberts (2002) furthered this idea of an impact on economic development when she outlined reduced labour supply, reduced labour productivity, reduced exports, and increased imports would occur due to HIV/AIDS. An area that has seen all three factors is the African Continent. In South Africa, the mining workforce has 60% of the people aged 30-44, but in 15 years, that is predicted to fall to 10% due to HIV/AIDS (Dixon et al., 2002). Also, 20% of student nurses are HIV positive, which puts a strain on resources (Dixon et al., 2002). There was a reduction in

productivity in Kenya, which ranged from $17 to $300, which forced the government to spend more, which created a potential financial crisis (Dixon et al., 2002). Finally, with both a smaller workforce and less production, many African countries face the dilemma of importing more and exporting less, which makes products more expensive to purchase (Dixon et al., 2002).

The cost of the HIV/AIDS pandemic in many economies is evident by how many resources are invested in programs or actions related to HIV/AIDS. In 2001, Gayle & Hill found that medical costs in 1990 to 1993 could range from $210USD to $936USD annually per person in African countries and in European countries; it could cost between $20,000USD to $57,000USD per person. Furthermore, most developing countries will see a decrease in treatment due to the rising cost of medication and a lack of medical infrastructure to provide adequate care for HIV-positive patients (Gayle & Hill, 2001).

While there is a loss from a lack of production or a lack of knowledge to continue production, some countries also face a loss in the social welfare system. This is because there is a possibility that "expenditures would also increase because of pension payments for AIDS-related deaths" (Bonnel, 2000, pg. 4). Also, the welfare system may have to pay disability payments, as in the case of Canada. The legal system has prohibited discrimination to those that have HIV/AIDS and under the Canadian Federal, Provincial and Territorial laws shown in Figure 2. As such, the welfare system has no choice but to also recognize HIV/AIDS as a disability and therefore must accommodate the needs and the medical expenses that HIV/AIDS positive people have. This recognition also places more costs or economic effect on the welfare system in Canada.

One example of the legal system creating more costs for the welfare system is in Ontario, where the Ontario Human Rights Code states (Ontario Human Rights Commission, 2020, para. 3):

> AIDS (Acquired Immunodeficiency Syndrome) and other medical conditions related to infection by the Human Immunodeficiency Virus (HIV) are recognized as disabilities within the Code'. All persons who have, or have had, or who are believed to have or have had, or are perceived to have, AIDS or HIV-related medical conditions, including those who do not show symptoms of AIDS or AIDS-related illnesses, are entitled to the protection of the *Code* in employment, services, housing, contracts and membership in trade unions.

Other parts of the world have also classified AIDS caused by HIV as a disability, impacting how much money governments have to spend per year or how much they can collect taxes (World Bank, 1997).

From a community perspective, the economic impact may be devastating to a community as those who used to work and provide for their families and contribute to the community may not be able to do so anymore due to HIV/AIDS. Many people diagnosed

with HIV/AIDS have lost their jobs or experience increased absence from work, sold assets, see a decrease in family income and increased expenditure (Taraphdar et al., 2011). The potential to earn more money is also an issue as people who live with HIV/AIDS have a higher dropout rate, affecting their career opportunities (Taraphdar et al., 2011).

The physical and economic effects of HIV/AIDS is important to understand as it is connected to the stigma that many have to endure after being infected with HIV/AIDS. For example, for a long time, HIV/AIDS was associated with the poorer parts of the world as many could not access proper education or treatment for the disease. The physical appearance of many people who were infected with HIV/AIDS created a certain stigma around those people, and many misconceptions have been developed about how somebody with HIV/AIDS looks like or where they come from. The economic effects affect stigma because people with HIV/AIDS may have been stigmatized to the point where finding work is an issue. The fact that Canadian provinces and territories have had to create specific laws to avoid discrimination is a clear sign that it is possible to progress from discrimination to stigma. An example of this is in sex work, where many sex workers are stigmatized solely based on their profession since the assumption is that they have HIV/AIDS. Understanding the physical and the economic effects of HIV/AIDS helps develop a clearer understanding of what people with HIV/AIDS go through and the actions that can be taken to help with de-stigmatization.

Stigma and HIV/AIDS

While physical and economic effects are a significant concern for many people, many of the same concerns about the physical and economic effects also played a role in the stigma that people with HIV/AIDS were given. Many of the stigmatizing behaviours derived from the physical damage that HIV/AIDS could do to a person, and many people facing economic hardships were also associated with HIV/AIDS due to their social level or because of their profession. The stigma attached to HIV/AIDS has impacted people's lives, and it is important to understand its effects.

Public Stigma

HIV/AIDS education is available in many countries, and people understand HIV/AIDS transmission methods. Today, HIV/AIDS is incurable, but many people can live a long and meaningful life with today's treatments. It is possible that people with HIV/AIDS show no symptoms or can test negative in a blood test for HIV with today's technology and medical advancements. While today it is unlikely that one could tell if somebody has HIV or not, previously, that was not the case. In the early stages of HIV/AIDS awareness during the 1970s, many people who had the disease were stigmatized, and groups of people were often associated with the disease due to misconceptions or the spreading of rumours. The HIV/AIDS Pandemic was called the 4-H Disease due to the Centre for Disease Control and Prevention releasing a statement saying that "the main at-risk groups, including partners of

people with AIDS, people who inject drugs, hemophiliacs and people who have recently been to Haiti (Avert, 2020). This was problematic since many people related to these four main groups were soon stigmatized, and very quickly, people referred to HIV/AIDS as the 4-H disease. The four Hs were homosexuals, hemophiliacs, heroin addicts and Haitians. This caused anybody associated with these groups to receive stigma by association on top of the public stigma they were already facing.

In public stigma, we can see that stigma, discrimination, and prejudice are all present as people who belonged to the 4-H club were often stigmatized, leading to discrimination and prejudice. Prejudice is seen predominantly as groups of people are assumed to have HIV/AIDS because they look a certain way or have a specific habit. Prejudice deals with unjustified and incorrect attitudes to a social group which homosexuals, hemophiliacs, heroin addicts, and Haitians associated with HIV/AIDS were subjected to by the community. The prejudice could often lead to discrimination and stigma since people might avoid them or treat them differently while also stereotyping them.

Self-Stigma

Many people who are HIV positive realize that "their HIV status is an extremely socially devalued aspect of the self, and this knowledge is experienced through at least three important stigma mechanisms: enacted stigma, anticipated stigma, and internalized stigma" (Earnshaw and Chaudoir, 2009, pg. 5). Before HIV/AIDS was well known to the public, one diagnosed with HIV/AIDS could see a disastrous effect on their lives and their family members' lives. Many people diagnosed with HIV/AIDS face stigma or discrimination from the community, lower self-esteem, negative beliefs about HIV/AIDS, mental health issues and an impact on the quality of life, to name a few (Earnshaw and Chaudoir, 2009; Tran et al., 2019). In fact, a socially devalued aspect of the self was usually taken where the person who has HIV/AIDS thought of themselves of having less value than other people. People with HIV/AIDS may also be stigmatized to the point where they feel worthless or inferior due to the high levels of internalized stigma (Helms et al., 2017). The study that was conducted by Helms et al. (2017) was a cross section study done between March of 2013 to January 2015 in Birmingham, Alabama. The study had 180 participants and the overall objective was to understand the "interpersonal factors affecting medication adherence" (Helms et al., 2017, pg. 238) in order to be able to develop interventions that would allow for better treatment adherence. The study concluded that "Higher levels of HIV-related internalized stigma, attachment-related anxiety (i.e., fear of abandonment by relationship partners), and concerns about being seen by others while taking HIV medication were all associated with worse medication adherence" (Helms et al., 2017, pg. 238). Within self-stigma, there is a heavy emphasis on discrimination that occurs, and as a result of such discrimination, self-stigma appears. With discrimination, in this case, people develop negative internal stereotypes and discriminating behaviours such as self-isolation, anxiety or enhanced fears.

Label Avoidance

Many people who have HIV/AIDS may be afraid to seek treatment because they perceive "the health care setting as intolerant and inaccessible" (Sayles, 2009, pg. 1101). People with HIV/AIDS may also avoid treatment or testing because they are afraid of being stigmatized. If the test is positive, it could be a constant stressor, which leads to a deterioration of mental health (Vanable et al., 2006). Much like TB, people with HIV/AIDS may be seen as 'damaged,' and a loss of employment or social opportunity may occur (Rutledge, 2009). Many of the misconceptions and stigma associated with HIV/AIDS were predominant during the rise of awareness of the pandemic. In more contemporary times, education and awareness-building/advocacy have changed some of the misconceptions about HIV/AIDS. With new medical technology, people may be able to avoid stigma altogether since the disease is manageable.

Label avoidance is found in nearly every country in the world, and it affects all people. For people that cannot afford treatment or do not have the means to get tested, then the result is that their life will be cut short. For those that can find or afford treatment, their lives can be next to normal. However, everyday life is turned upside down when the person mentions that they have HIV/AIDS. In developed countries with the medical infrastructure and medical staff, HIV patients are still stigmatized, which has severe consequences on the person with HIV/AIDS (Helms et al., 2017). One may assume that in developed countries, the education programs and technology would help stop the spread of HIV/AIDS and reduce stigma due to the large number of resources at their disposal, but this is not the case. We associated education, technology and HIV/AIDS together because of public awareness campaigns or initiatives that have been used to already bring awareness and the increased use of technology allows for better distribution of information and understanding of the disease. The developed countries can access technology to help create medication, further current research and find innovative ways to prevent the disease. In addition to technology, the education program that many developed countries have results from a well-established health system that can educate people on infectious diseases. This may not always be the case as seen in the United States and Canada, parts of the country have higher stigmatization due to the nature of the community that they are in or the industry that they participate in, such as the US deep South and sex work (Helms et al., 2017; Logie et al., 2011). Speculation by Helms et al. (2017) is that due to the lower education and the religious learnings, a higher level of stigma is developed. In developed countries, with the medication available for people living with HIV/AIDS, the stigma may cause them to stop taking the medication (Helms et al., 2017). The correlation between stigma and lower medication adherence was found in Helms et al.'s (2017) research where the results were that "internalized stigma leads to attachment-related anxiety, which leads to concern about being seen while taking HIV medication, which in turn leads to poor medication adherence" (Helms et al., 2017, pg.7). Some people that take medication for HIV/AIDS will take them in seclusion to avoid being seen and to conceal their HIV positive status, leading to inconsistent medication intakes and a higher chance for a resurgence of HIV cells in their body (Helms et al., 2017).

Stigma by Association

While there is a general effect of stigma and discrimination for people living with HIV/AIDS, many specific groups of people are targeted or face a harsher reality than others only because they are affiliated with a particular group of people or because they come from a specific country. Most predominantly, there is a large amount of stigma and discrimination towards people who identify as gay, sex workers and drug addicts. Many men and women who identify as gay, lesbian, bi-sexual, transgendered or queer experience stress due to the stigma that cast towards them. This is because HIV/AIDS has been historically attributed to the men and women identified as Gay or Lesbian (Herek and Capitanio, 1999). As a result of the stigma, there has been an increase in mental health issues such as self-reported sexism, depression, anxiety and eating orders within these populations due to people's misconceptions (Logie et al., 2011). Furthermore, gay men were found to have had their HIV/AIDS progression increase due to the public rejection they faced (Cole et al., 1997).

Some may see that HIV/AIDS is a "Gay man's disease" (Logie et al., 2011, pg. 7). In Logie et al.'s study (2011), they conducted 15 focus groups interviews in five cities in Ontario, Canada, with 104 HIV positive women, and one of them stated that HIV/AIDS was a " 'gay man's' disease: 'most of these Aids Service Organizations do not cater specifically for women. I think that comes from the fact that long back HIV and AIDS was well known to be a white gay man's disease." (pg.7). This statement shows two gendered effects that society has placed: first, HIV/AIDS is related explicitly to homosexual males and that women are cut out of the picture since there are no services for them. HIV/AIDS has a multiplying effect on those that identify as gay, bi-sexual, queer or transgendered because there is already stigma cast upon these people. Still, at the same time, many receive stigma by association just for identifying as one of those groups of people. An interviewee from Logie et al.'s study stated that sexual minorities are seen as "'demonic' and HIV as a 'gay disease' and 'they see you being queer as being demonic or evil'" (pg.7). Transgendered members of the community face even more scrutiny because many automatically assume that they already have HIV/AIDS. In one case, a transgendered refugee was applying for refugee status in Ontario, Canada and was rejected since the immigration officer thought they were "a prostitute with HIV" (Logie et al., 2011, pg. 8). This severely undermines many people as the stigma by association affects the transgendered people and sex workers. There are assumptions that if you are either a sex worker or a transgender or both, you must automatically have HIV/AIDS.

Logie et al.'s (2011) study revealed through the focus groups and interviews that many sex workers who are female also face stigma from friends, family and the community and will not disclose their HIV positive status to others because they fear or have been already stigmatized. Many have "lost friendships or have had people distance themselves from the person due to an HIV positive status (Logie et al., 2011 pg. 8). The people who work in the sex trade are stigmatized, and the kids related to sex workers are also stigmatized. The first set of stigma is because the parent or relative is in the sex trade or works as a sex worker, but this is made worse if the parent or relative is HIV positive (Logie et al., 2011).

Health Practitioner Stigma

In some countries, health care workers are afraid to provide treatment because they are afraid of contracting the disease (Turan et al., 2008). An example of health care workers stigmatizing HIV patients would be in the dental field. A study run by Patel et al. (2014) in Ohio, USA, saw that HIV patients that were going to the dentist noticed a behaviour change which included avoiding eye contact, declining dental care, double gloving before a procedure, making appointments at the end of a session or day and other actions that were not normal to any medical profession. Patel et al.'s (2014) study intended to understand the stigma of HIV/AIDS in the dental profession. The study was a cross-sectional study of 60 adults, and audio recorded interviews were conducted. The interviews had four open-ended questions used for analysis (Patel et al., 2014). The results of Patel et al.'s (2014) study were that "Twenty-seven participants (45%) reported ever having anticipated being judged, stigmatized or treated with disrespect in a dental setting due to HIV status" (Patel et al., 2014, pg. 22). The study further discovered that many concerns of the people interviewed were about receiving humane and respectful treatment, any judgments or stereotypes about giving HIV to the dentist, and the dentist's fear and the confidentiality that they should have. (Patel et al., 2014).

Table 3. HIV/AIDS Stigma Summary

	Where Stigma Occurs	**Stigmatizer**	**Who is Stigmatized**	**Consequences**
Public Stigma	In the general community of villages and cities. Public stigma due to TB can be found anywhere.	The general public, family members, co-workers	Men and women that have contracted HIV/AIDS	Misconceptions of what people with HIV/AIDS did and wrongful associations of different groups of people to HIV/AIDS.
Self-Stigma	Internally	A person with HIV/AIDS	Men and women that have contracted HIV/AIDS	People with HIV/AIDS who self-stigmatize have lower self-esteem, negative beliefs about themselves, mental health issues, the impact of the quality of life,

				fear of abandonment by relationship partners, and medication adherence issues.
Label Avoidance	In the general community of villages and cities. As well as treatment centres, medical facilities, doctor's offices, etc.	The general public, family members, co-workers	Men and women that have contracted HIV/AIDS	Patients with HIV/AIDS may stop taking medication or take the medication in an area not seen by others.
Stigma by Association	In the general community of villages and cities.	The general public, family members, co-workers	Men and women that have contracted HIV/AIDS	Groups of people such as Sex workers, transgendered people and members of the LGTBQ+ community are wrongfully associated with HIV/AIDS
Health Practitioner Stigma	Treatment centres, Medical facilities, doctor's offices, etc.	Health Care Workers such as doctors, dentists, nurses etc.	Men and women that have contracted HIV/AIDS	Health Care Professionals will perform additional actions during procedures because of personal bias and misconceptions about HIV/AIDS. An example would be double gloving during a dentist appointment.

De-stigmatization Campaigns

While many people may be suspicious of or stigmatize and discriminate against people who have HIV/AIDS, many government organizations, along with not-for-profit organizations and grassroots campaigns, have fought hard to de-stigmatize HIV/AIDS. Many groups have had to educate the public, and while they were educating people and creating awareness, they also had to battle with misconceptions and rumours that people fought back with. Stigma is not only about the disease of HIV/AIDS, it is true and evident that those that have HIV/AIDS are stigmatized but there is more to it than just having the disease. The attributes that are involved with HIV/AIDS. People have associated HIV/AIDS to different groups of people, specific jobs, to other diseases and even sexual orientation. The de-stigmatization efforts do not concentrate on just those that have the disease; it also focuses on de-stigmatizing those attributes that are wrongly associated with the disease as well. This part is also important since it impacts the lives of people that do not have HIV/AIDS but are assumed to have it based on how they look, what they do or what they believe in.

There has been a mix of organizational and grassroots campaigns and initiatives to de-stigmatize HIV/AIDS. Some formal methods include campaigns from the government and programs or laws that have been enacted to help reduce discrimination. For example, in many legal systems, there is a formal recognition that a person with HIV/AIDS is classified as a disabled person and, as such, cannot be discriminated against under any circumstance, as stated before. If somebody with HIV/AIDS is qualified for a job or benefit, the provider must provide such a service or opportunity. Examples of such a law are found in the Canadian and American legal systems. In Canada, the Charter of Rights and Freedoms, under Section 15 it states:

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

In the United States, the Americans with Disabilities Act protects Americans who have a disability from being discriminated against (ADATA, 2020). In 1998 the law case Bragdon v. Abbott - 524 U.S. 624, 118 S. Ct. 2196, it was decided that her “HIV infection was classified under the ADA, even though her infection had not yet progressed to the symptomatic stage. 107 F. 3d 934, 939–943 (Bragdon v. Abbott, 1998, pg. 630). These two law cases are examples of the formal de-stigmatization of HIV/AIDS. It shows that the law is willing to put restrictions on discrimination of a person with HIV/AIDS, and as such, it provides the opportunity for those infected to live close to everyday life. The Canadian Charter of Rights and Freedoms and the Americans with Disability Act ensures that discrimination should not occur, which is an important part of de-stigmatization as it reduces unfair treatment towards people with HIV/AIDS. This formal action is not a direct action for de-stigmatization, but it does help in de-stigmatization of HIV/AIDS.

While both of these laws ensure that people with HIV/AIDS have treated like normal people, the main target, it would seem, is targeting discrimination. But this formal action against discrimination can help with the de-stigmatization of people with HIV/AIDS through the normalization of hiring and interacting with people with HIV/AIDS.

While many people see that the legal battle for HIV/AIDS has reached a point where it provides people with opportunities to live everyday lives without discrimination, many grassroots and non-governmental organizations are also playing a role in de-stigmatizing HIV/AIDS. One example of this form of de-stigmatization is from the magazine *The Vangardist* by Julian Wiehl. In 2015, they printed an entire issue of their magazine with HIV positive blood mixed into the ink. The Vangardist is a German Magazine company that targets young males that live in an urban setting. The magazine is seen as more progressive compared to others. All 3,000 of their "printed edition was 1 part blood to 28 parts ink, with some blue ink to highlight its "Heroes of HIV" theme" (Bernstein, 2015, para. 3).

Furthermore, the magazine came in "a sealed wrapper, forcing the reader to "break the seal to break the stigma" (Bernstein, 2015, para.4). This act of de-stigmatization is quantitatively measurable through the number of people it reaches. There were 3,000 copies sold and delivered; however, other numbers such as social media that are less conclusive or direct with the number of people impacted. What is essential to understand is that while this is a smaller campaign, it has impacted more people in thinking about HIV/AIDS differently. The Vanguardist is a form of de-stigmatization that targets stigma as it breaks the negative stereotyping and discriminatory behaviour by allowing people to see that holding something printed in HIV positive blood is okay.

In 2018, the Minister of Health of Canada announced on December 1st or World Aids Day that Canada was still committed to reducing HIV/AIDS stigma through its financial contributions and that Canada was still committed to the global HIV targets. The 17 Sustainable Development Goals (SDGs) are included "ending the AIDS epidemic by 2030, and meeting the UNAIDS 90-90-90 treatment targets by 2020:90% of people living with HIV know their HIV status; 90% of people with diagnosed HIV infection are on treatment; and 90% of people receiving treatment have viral suppression (Public Health Agency of Canada, 2018, para. 6). The SDGs are a UN initiative from the Millennium Development Goals (MDGs) started in 2000 (United Nations Department of Economic and Social Affairs, 2020). The MDGs were a 15-year project, and in 2015, when the project was completed, the SDGs were created to help continue the work done (UNDESA, 2020). Due to Canada's commitment to ending HIV/AIDS stigma, it has committed to investing $132 million over five years to "support the work of community-based organizations in addressing HIV and other sexually transmitted and blood-borne infections." (Public Health Agency of Canada 2018, para.12). Furthermore, it has invested $87 million from 2018-2019 "to support surveillance, prevention, public health guidance, knowledge development and a robust pan-Canadian community-based response to HIV, hepatitis C and other sexually transmitted and blood-borne infections and $804 million for the "Global Fund to Fight AIDS,

Tuberculosis and Malaria." (Public Health Agency of Canada 2018, para.13 -14). Canada's commitment is an example of a formal or organizational campaign that has used a day such as World Aids Day on December 1st to raise awareness about HIV stigma while also providing support to help end stigma and HIV/AIDS.

The commitment that Canada has publicly stated is not a direct action that impacts the de-stigmatization of HIV/AIDS. However, with the financial support that the Canadian Government has stated, part of the funding helps with de-stigmatization as education is a key factor when trying to de-stigmatize HIV/AIDS. The actions that the Canadian government has taken are important for de-stigmatization as it not only reduces the number of people infected and gives the community the necessary resources to help those with the disease through treatment and social support.

In the United States of America, the Centre for Disease Control and Prevention has initiated a campaign called 'Let's stop HIV together.' This Campaign is a part of a more massive National Campaign in the United States called "Ending the HIV Epidemic: A Plan for America. The initiative aims to reduce new HIV infections in the U.S. by 90% by 2030" (CDC, 2020). Such an initiative has provided people with a platform to voice their experiences and has been able to allow for public education to occur in areas that may have a high level of discrimination. The Ending the HIV Epidemic campaign used US $126.8 million in 2019 to reduce new HIV infections and develop key initiatives to help provide prevention and treatment programs (CDC, 2020). In addition to the money that the national plan has been able to use in 2019, the Let's Stop HIV Together campaign has about 20,000 followers on social media, but only a fraction of that is notified when they post something.

The campaign that the CDC has in place here does not directly target stigma, but rather, it targets discrimination and prejudice as the aim of the campaign is to help give a voice to express voices, which will hopefully change people's perception. After such changes, it may be possible to correct the prejudice that was there and possibly have discriminating behaviours stopped. The social media campaign that they have launched also targets prejudice as it tends to develop factual and correct information to inform people.

Another example of de-stigmatization would be when celebrities are actively promoting a specific message. With modern technology being so advanced and so connected to our lives, it can quickly spread the word when a celebrity talks about a specific cause. There have been a few celebrities that have promoted the fight against HIV/AIDS to the public. One of them was the late Princess Diana, who championed the fight against stigma towards HIV patients. She started in 1987, where she opened the first treatment wing for HIV patients, and during that opening, the media was able to take photos of her shaking hands with HIV/AIDS patients, which struck a powerful message around the world (Cope, 2020). This message was spread across the globe through media outlet sources, and because of her actions, it has continued support for the de-stigmatization of HIV/AIDS through her children (Cope, 2020). While not evident by the number of people impacted, the impact is shown in news articles. In 1987, it was the height of the HIV/AIDS pandemic and in the United States,

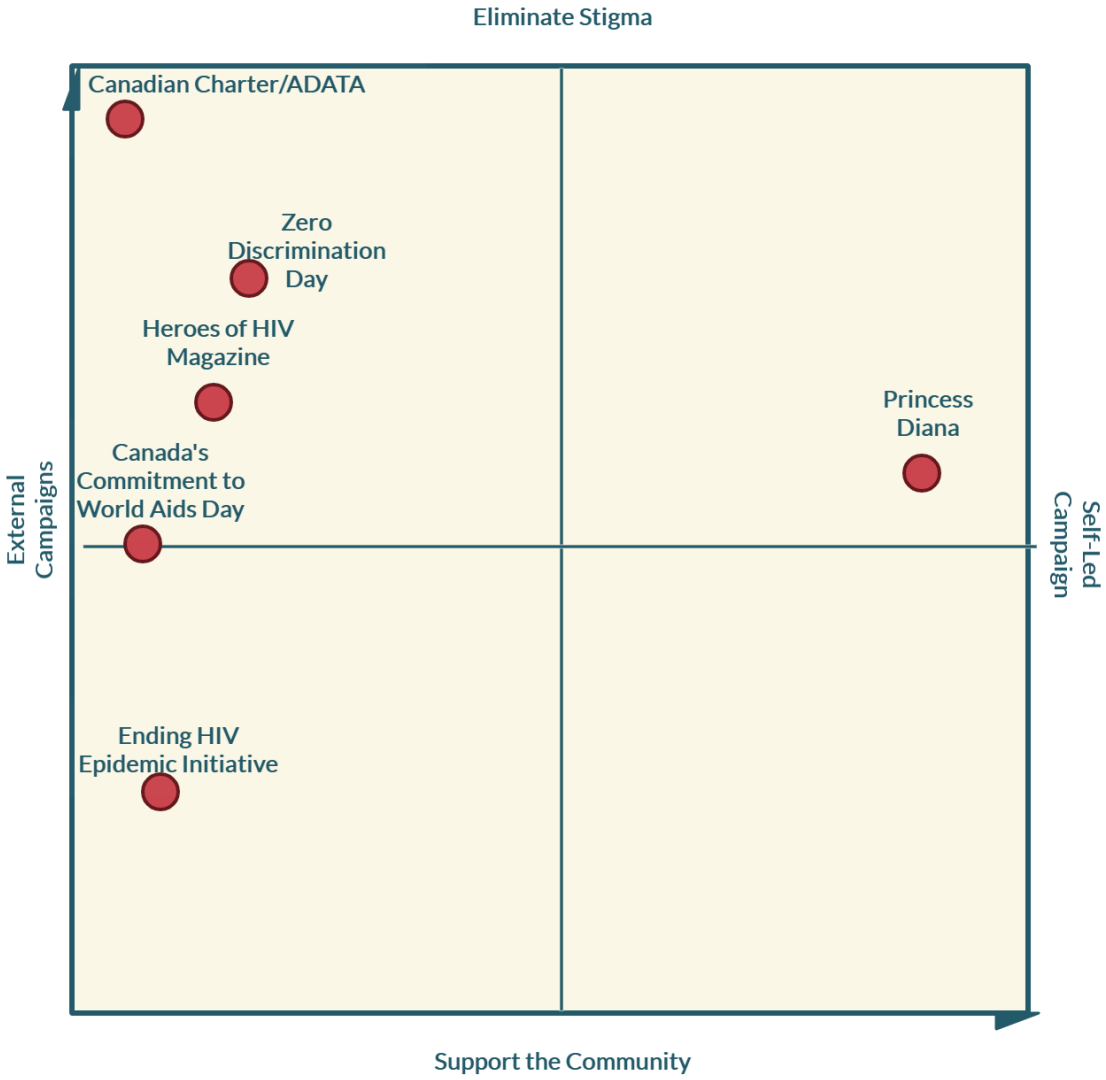
and experts were unsure how to proceed effectively. Some experts stated that there is no danger in a peck on the cheek of an infected person, but they recommend against any exchange of saliva and deep kissing with an infected person" (Laing, 2017, para.2) and when Princess Diana was seen shaking hands with such patients, it helped "publicly challenge the notion that HIV was passed from person to person by touch." (Cope, 2020, para 4.). While there are no numbers or statistics that can be pulled to show the number of people impacted, what can be seen is that she paved the way for her sons as well as other organizations to de-stigmatize HIV/AIDS.

Princess Diana's actions helped de-stigmatization by addressing the prejudice that the general public had towards people that were HIV/AIDS positive. Her actions that challenged the public's notion that HIV was passed from person to person are challenging the prejudice that the public has towards HIV/AIDS positive people. However, her actions do directly affect stigma or discrimination. The effects of stigma and discrimination may be reduced due to Princess Diana's actions' which may have changed perceptions and prejudice. Many people who stigmatized HIV/AIDS positive people might have had a second thought after seeing Princess Diana shaking hands with HIV/AIDS patients. It is difficult to say if the effect was immediate, but we know that there was an impact.

On the other side of the world in Asia, UNAIDS helps Asian countries de-stigmatize HIV/AIDS within their communities. UNAIDS is a joint program that brings together eleven UN organizations, including the UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, UN Women, ILO, UNESCO, and WHO and the World Bank (UNAIDS, 2020). One of their programs that have been quite successful is in Thailand at the Bamrasnaradura Infectious Disease Institute in Nonthaburi. The campaign was supported by the Thai Government and the Ministry of Public Health. The campaign was launched by Chalatit Tantiwut, a Thai singer and UNAIDS National Goodwill Ambassador for Thailand (UNAIDS, 2020), who encouraged everyone to join the Zero Discrimination movement. Every March 1st, Thailand recognizes and participates in Zero Discrimination Day. The program was so successful in Thailand that Vietnam and The Lao People's Democratic Republic began piloting and adapting the initiative while Myanmar has "Myanmar has expressed its interest in using a similar program. (UNAIDS, 2020).

The UNAIDS campaign that partnered with Thailand and other Asian countries is not a direct campaign or de-stigmatization action. Much rather, the campaign targeted the discrimination that many people in Thailand face when they are known to have HIV/AIDS. While it is not a de-stigmatization campaign or an action that is directly impacting the de-stigmatization of HIV/AIDS, it does impact part of the issue with stigma and HIV/AIDS. With the support of Zero Discrimination Day from UNAIDS, Thailand and other Asian countries have seen it is possible that the discriminating behaviour that accompanies stigma may be reduced and that perceptions about HIV/AIDS also changes to the point where stigma and discrimination are reduced.

In Figure 1.2, the de-stigmatization chart for HIV/AIDS, all the de-stigmatization campaigns have been plotted.



Future Interventions for De-stigmatization

The future of de-stigmatization is one that must adapt to current needs and current technology. Much like how HIV/AIDS has been slowly controlled and prevented, de-stigmatization must be seen in the same way. De-stigmatization does not happen after one campaign or event because it has been developed into people's minds and community norms for such a long time. The HIV/AIDS stigma has been able to develop since the 1960s and 1980s, which many people see as the norm, and it will continue to unless we begin to break the cycle of stigmatization.

One of the biggest impediments to HIV/AIDS prevention is HIV/AIDS stigma (Mahajan et al., 2008). Currently, the main focus is on reducing HIV/AIDS cases, and many organizations have identified that prevention is one of the better ways to do so. However, due to stigma, there is a "low uptake of and poor adherence to prevention and treatment services" (Mahajan et al., 2008, pg. S 72). Often, the stigma's impact is not recorded, or the program's effectiveness is not recorded, which means a valuable metric is lost when trying to find how effective programs are working (Mahajan et al., 2008). Mahajan et al. (2008) recommend moving forward with a comprehensive and conceptual framework for HIV/AIDS stigma and using valid and reliable stigma measuring tools by research projects. The article further suggests that there needs to be a promotion of supportive social and legal frameworks that "minimize unintended consequences of provider-initiated opt-out HIV testing," implement stigma reduction interventions among healthcare providers; and support further research on the relationship between stigma and provider-initiated opt-out HIV testing (Mahajan et al., 2008, pg. S 76). Finally, Mahajan et al. (2008) suggest that some countries' current laws contribute to stigma and discrimination. As such, there needs to be a push for the repeal of laws and policies that reinforce stigma towards vulnerable people. In summary, Mahajan et al. (2008) suggest that the approaches to reduce stigma must be multilevel and multifaceted to allow for the stigma to be captured at all levels and that the programs available must break the dominant social order.

Another path that de-stigmatization should look at is the research conducted when it comes to stigma. Parker & Aggleton (2003) suggests that there needs to be further development in conceptual studies, investigative studies and strategic and policy-oriented research made to assist in the contributions of "the development of programmes and policies aimed at effectively reducing the human suffering...that is a direct result of unmitigated HIV and AIDS-related stigmatization and discrimination" (pg. 20-21). They suggest that the research that will influence the new programmes and policies must go further than the models seen today and are used in the field.

While some interventions will work in specific countries or countries of similar culture and economic ability, the same interventions may not work for developing countries or other countries with different cultures. Brown et al.'s (2003) study discusses this issue through a review of 22 studies that tested "a variety of interventions to decrease AIDS stigma in developed and developing countries" (Brown et al., 2003, pg.49). The study found that the majority of the study was aimed at increasing the tolerance of people living with HIV/AIDS while the minority of the studies were testing the interventions "to increase willingness to treat PLHA among health care providers or improve coping strategies for dealing with AIDS stigma among PLHA or at-risk groups (Brown et al., 2003, pg.49). The results of the review suggest that for the future of de-stigmatization in HIV/AIDS, there have to be more campaigns or initiatives to help reduce HIV/AIDS stigma, but such campaigns and initiatives need to be thoroughly and rigorously studied, and the results must be published to the public. Furthermore, there must be an understanding of what campaigns or initiatives will work in different countries. For example, Brown et al. (2003) mention that "inducing empathy for PLHA through direct contact has proven successful in reducing stigma and increasing

positive attitudes in the United States. However, we do not know much about how well this approach works in developing countries (pg. 66).

Other ideas that need to be explored to better de-stigmatize HIV/AIDS is research on the results of national or large campaigns or initiatives to gain data on the effects of mass media. With the effects of mass media needed to explore Parker & Aggleton (2003) hypothesis that the new way forward is to use the community's mobilization to resist stigmatization and discrimination while also using structured interventions to create a social climate that rejects stigmatization and discrimination. Brown et al. (2003) state that multimethod approaches can reduce stigma short term and on a small scale, but they suggest that research is needed on the larger scale efforts and that the evidence that is needed is

> "of multichannel, comprehensive programs, targeting whole communities, not only health workers or PLHA, whose lives are centred within complex worlds in their own communities and whose reaction to the stigma of AIDS will be influenced by the community's norms (pg.66).

Tran et al. (2019) agrees with this notion when they state that HIV stigma research should be looking at a combination of different approaches and interventions that will be multi-tier. An intervention example would be one that incorporates "community-based and mass media communication to elevate its value and reduce discrimination within the population, hence, improve multiple outcomes such as mental health status, substance use, social isolation, and employment" (pg.17). Tran et al. (2019) further expands on Parker & Aggleton's (2003) idea by stating that the research must develop concrete and empirical data in different contexts to reduce stigma (Tran et al., 2019). Tran et al. (2019) suggests that to sustain the progress made by the stigma-reducing interventions that there needs to be counselling and psycho-behavioural interventions for people who have HIV/AIDS.

Brown et al. (2003) also suggested that research in developing countries de-stigmatization recommended examining the effects of increased access to drugs may have on the reduction of stigma as "some infectious diseases can probably be traced to the availability of drugs that have cured, masked, or delayed the onset of final illness or at least treated the worst symptoms of the diseases (Macintyre & Macdonald, 2000 as cited in Brown et al. 2003, pg. 67)

Finally, the way HIV/AIDS stigma is looked at today with so many celebrities supporting causes to end HIV/AIDS and to break the stigma that is projected on people is helpful. Still, in many cases, the extent of what they can do is limited. The promotion of HIV/AIDS prevention for celebrities helps celebrities gain positive images, but they do not help the de-stigmatization of HIV/AIDS. For example, Magic Johnson has a significant impact on promoting HIV/AIDS prevention but very little has been written about how it helped de-stigmatization (Brown & Basil, 1995). As most researchers have stated, the future of HIV/AIDS's de-stigmatization will be multi-tiered and multi-faceted. It must first reach all society levels and create awareness in people to reject stigmatizing behaviour. The campaigns

needed are not the campaigns that we have right now. Most campaigns target prevention but do not change social norms and ideologies that people already have about those who carry HIV/AIDS. There is a need for governmental organizations, not-for-profit organizations, and grass-root campaigns to target people and society's mentality while also collecting empirical data of the campaign's effects to make progress. There is also a need to help break the cycle that HIV/AIDS patients suffer from, self-stigmatization and poor mental health through programs that can support them with recovery and growth.

SARS

The final disease that will be examined is Severe Acute Respiratory Syndrome, also known as SARS. The section will explore the historical background of SARS and why it is considered an infectious disease. After the discussion, it will move on to the effects it has on individuals that contract SARS and the rest of the community. The final section will examine the link between stigma and SARS and examine the initiatives that have de-stigmatized SARS. This section aims to understand the processes that have worked and why they have worked for de-stigmatization, and how it can be used for future infectious diseases. It is crucial to map out these actions as they may provide useful insight into the future. An aspect that de-stigmatization campaigns have taught us from SARS is that the media is a powerful tool, and the media can increase the chances for a specific population to be stigmatized. From SARS, we learned that stigma could occur within a race where you can see Asians stigmatizing Asians. There is a background portion in this section because the history of SARS and the physical and economic effects of SARS on those that are stigmatized relate to de-stigmatization and how the community developed stigmatizing behaviours towards East Asians. The origins of the disease can explain the stigma towards East Asians, and the physical effects contribute to the stigma that is witnessed and experienced by Asians. For example, SARS has a symptom of coughing, and in one example provided by Leung (2008), coughing on a subway train could get people to stigmatize you if you were Asian.

Background on SARS

Severe Acute Respiratory Syndrome or SARS is “a viral respiratory illness caused by a coronavirus” (CDC, 2017, para.1). The coronavirus for SARS has been named SARS-COV. This virus was not originally a virus that affected humans, but rather it is a mutated form of a coronavirus found in animals (WHO, 2020). There has not been any determination about which animal exactly SARS-COV came from, but many experts speculate that it came from bats or other animals such as civet cats (WHO, 2020). SARS was the first pandemic that the world faced in the 21st century (LeDuc & Barry, 2004). Before SARS, the world had only dealt with a handful of pandemics, such as the Black Death during the 14th Century, the Spanish Flu in 1918, and the HIV/AIDS Pandemic starting in the 1960s (Newman, 2020) many flu pandemics such as the H1N1 Swine Flu, H5N1 Avian Flu, and Influenza B have been dealt with and are continued to be dealt with by countries around the world.

The first SARS case was found to originate from Guangdong province in southern China on November 16, 2002 (CDC, 2013). By March of 2003, the World Health Organization issued a global alert for a “severe form of pneumonia of unknown origin in persons from China, Vietnam and Hong Kong” (CDC, 2013, para 3.). By July 5th, 2003, the last restrictions for alerts were removed. The only SARS case after July 5th was on September 8th in Singapore. A researcher had an accidental contamination incident that caused the case (Kamps & Hoffmann, 2003). From March to July, 8096 people were infected, of which 774 died. SARS affected 30 countries around the world, spanning every continent (WHO, 2015). The virus started its spread in Hong Kong, and it rapidly spread to other

countries such as Canada, the United States, Vietnam, and Singapore. Since the last case of SARS-COV in 2003, it has not reappeared. While the specific SARS Coronavirus has not re-emerged, other coronavirus strains have developed, such as the Middle East Respiratory Syndrome in 2012 and COVID-19 in 2019/2020.

Effects of SARS

The SARS virus is transmitted by "respiratory droplets (droplet spread) produced when an infected person coughs or sneezes" (CDC, 2017, para. 4). The droplets produced by the infected person can enter the body through any "mucous membranes of the mouth, nose, or eyes" (CDC, 2017, para. 4). This transmission can occur if somebody inhales droplets from an infected person or touches an object with infected droplets on its surface and touches their mouth, nose, or eyes (CDC, 2017). Usually, the transmission will begin during the second week of receiving the infection (WHO 2020). Researchers are still unsure if SARS can be spread through airborne particles.

Physical Effects

The physical effects of SARS begin with a high fever of over 100°F or over 38°C (CDC, 2017). The disease will continue with flu-like symptoms such as malaise, myalgia, headache, diarrhea, and shivering (rigours) (WHO, 2020). Other symptoms that may appear are a dry cough, shortness of breath, sore throat, difficulty breathing, hypoxia and headaches (Johns Hopkins, 2020; WHO, 2020). In a serious case, the person's condition may rapidly deteriorate and lead to respiratory distress, requiring intensive care to treat (WHO, 2020). SARS may complicate one's ability to breathe, but it is also possible that the patient develops pneumonia, which leads to a significant strain on the immune system. Pneumonia is an infection of the lungs, which can also complicate the effects SARS has on a person. While SARS infection is a serious matter, not all children or adults exposed to SARS will become sick (Johns Hopkins, 2020).

Economic Effects

If a person has been infected with SARS it can impact them physically, but SARS' economic impact was more than at the individual or a community-level (Gupta et al., 2004; Keogh -Brown & Smith, 2008). SARS created an economic ripple effect that was felt around the globe. While many diseases can have a specific financial impact or cause a family to suffer from a loss of income or a loss of social status, SARS affects most people economically due to the travel restrictions. SARS has affected specific groups of people through the location of the country or city such as Toronto and Hong Kong. As such countries and the GDP of countries affected did suffer. In Keogh-Brown and Smith's (2008) article, they found that countries that had SARS restrictions were mostly impacted when it came to factors such as the GDP, tourism, and investments. Keogh - Brown and Smith's (2008) research used statistical data from several years to compare SARS' macroeconomic impact on affected countries. The research took all of the countries that had SARS cases. Then the researchers looked at key indicators such as GDP, GDP Growth, Exports and trade,

and government budgeting. Other areas that were examined were the expenditures for health services, the revenue on tourism, hotels, airlines, retail, restaurants, entertainment and the Information Technology sector. The examination of these areas or sectors showed the researchers if there was any impact due to SARS. The GDP's impact is evident, as the gathered research showed a loss in some of the examined countries. For example, Canada lost $3.2 Billion to $6.4 billion during SARS, while Singapore lost $4.9 billion, and Hong Kong lost $3.7 billion (Keogh-Brown & Smith, 2008). Other areas showed decreased growth and exports and trade, tourism, food, and travel (Keogh-Brown & Smith, 2008). One important aspect that should be noted is that in the next quarter, most if not all of the countries that had an impact economically were able to recover and even gain profits (Keogh-Brown & Smith, 2008).

Another example of the economic effects that occurred was the quarantine imposed on cities such as Toronto. Gupta et al.'s (2004) study explored the total cost of money that SARS had on the City of Toronto. The study used two scenarios to calculate whether setting quarantine early on in the pandemic would be more cost-effective than waiting. The study only looked at the City of Toronto and how SARS affected the city. The study also used estimates that were based on the data that was collected beforehand. Gupta et al. (2004) found that the quarantine method would have been the best method for Toronto to proceed and based on the research that was completed they determined that "had SARS been identified in the index patient, or even the primary or secondary infections, the city may have been spared the enormous economic burden of disease that descended upon them in 2003" (pg. 392). Due to the quarantine, the City of Toronto saw a $42.2 million cost for the quarantine they put people through (Gupta et al., 2008). While the City of Toronto saw a $42.2 million cost, the analysis that Gupta et al.'s (2008) study also shows what might have happened if the city did not go into quarantine immediately, and the results showed that the cost would have been far greater.

From a family or individual perspective, the quarantine affected many aspects of life. Cities became significantly less busy than before, which is what Qiu et al.'s (2018) study found. Qiu et al.'s (2018) article *The Impacts on Health, Society, and Economy of SARS and H7N9 Outbreaks in China: A Case Comparison Study* was conducted through a qualitative case study approach that reviewed literature, document analysis and in-depth interviews. The article looked primarily at China's impact, and it used books, journal articles, government documents, policy reports, conference papers to formulate their research. The interviews were semi-structured, and 26 key stakeholders were interviewed about their "experience of and reflections on the emergency management of the SARS and H7N9 events, with the same questions about the impacts on health, society, and economy of SARS and H7N9" (Qiu et al., 2018, pg. 2). The study found that once the WHO announced that Beijing was the epidemic area, Beijing "became a ghost city. We all know that Beijing has traffic jams every day, but [then] you worried whether you were speeding" (Qiu et al., 2018 pg. 2) since there was no longer any traffic. Many people were told to stay home, and as a result, jobs were suspended in manufacturing, and tourism was also suspended, which led to an impact on workers' ability to make a living. Furthermore, there were fewer interactions between people as there

was a fear of infection, leading to decreased income. Qiu et al.'s (2018) interviews revealed a reduction of average income to $175.44, 22.36% below what is expected.

Stigma and SARS

While economic and physical burdens were a significant concern for many people worldwide, a specific stigma was attached to particular people who contracted SARS or were perceived to be at a higher risk of spreading or contracting SARS. Hong Kong was a city that was heavily impacted by SARS, and it had one of the highest infection rates and death rates compared to other countries or cities. As a result, a study was developed to understand the impact of stigma on the people who had SARS.

Public Stigma

This stigma was explored by Lee et al.'s (2005) study, where they did surveys, interviews and statistical analysis on the specific living residence, Amoy Gardens. Amoy Gardens was one of the hotspots in Hong Kong that saw one of SARS's largest outbreaks. To understand what questions should be asked, Lee et al.'s (2005) study began with two focus groups that lasted over an hour each (Lee et al., 2005). Fifteen residents participated in the focus groups, of which six were a part of the Amoy Gardens Association executive committee. The focus group's structure was of an unstructured format to get a personal or observed experience of stigma among the residents that were "ex-SARS patients and their family members as well as non-infected residents" (Lee et al., 2005, pg. 2040). After the focus groups, a questionnaire was developed and placed in 4896 mailboxes. From the questionnaire, there were seven people contacted for interviews and the data was eventually statistically analyzed. The results showed that 88.1% of residents said there was an impact on their daily social life. Many participants stated that there was a rejection from others for going out, home delivery services refused to come, maintenance services, clinics, and hotels refused service, domestic helpers requested reassignment, and people would move away in restaurants. (Lee et al., 2005).

Other aspects of people's lives were affected by SARS, such as in the workplace. Many of the questionnaires showed discrimination or stigma placed on ex-SARS patients by co-workers and employers. For example, employers and co-workers told people who had SARS to work from home, show a clean health bill, take annual paid or unpaid leave, work alone in a room, or self-quarantine (Lee et al., 2005). Some residents even reported extreme behaviour such as getting fired, receiving verbal abuse, getting shunned; having objects they touched sterilized before use, and being told to wear a mask in the office (Lee et al., 2005). The physical stigma that many victims felt after SARS came from all walks of life. Doctors would not see them, employers treated them differently, and even co-workers, friends and family members treated them differently because of perceived stigma or stigma by association with Amoy Gardens' residents.

While co-workers and employers could discriminate, the general public did so as well. In New York City, specifically Chinatown, many Chinese Americans that lived there were discriminated against during SARS. Institutions that were located in the area lost business, and many Chinese people were stigmatized. Laura Eichelberger's article *SARS and New York's Chinatown: The politics of risk and blame during an epidemic of fear* showed the stigma through discrimination and prejudice shown towards Chinatown even though they did not receive any cases (Eichelberger, 2007). Eichelberger's study had 37 semi-structured, open-ended interviews with community members found using opportunistic and snowball sampling of different sectors of Chinatown's neighbourhoods (Eichelberger, 2007). Her study was limited due to a language barrier and a lack of trust from the community. Those that were interviewed came from an immigrant background and were somewhat educated.

The results of the research showed that many interviewees faced prejudice on several fronts. The museum located inside Chinatown faced a loss of "a tremendous amount of visitors the week that SARS was initially broadcast in the news...We had schools calling in and saying, "Yeah; we have a lot of students and parents that are afraid to let their children go to Chinatown" (Eichelberger, 2007, pg. 1289). Other people in the community stated that the term" coughing while Asian" became a stereotype and that "if there was an Asian coughing on a train, people would look at them nasty, and move away" (Eichelberger 2007, pg. 1289). Chinatown and the Chinese culture became stigmatized during SARS because the media showed how Asian countries spread SARS, and some local delicacies in Chinese cuisine, such as civets, a small cat-like creature was able to have the SARS virus (Eichelberger, 2007). Finally, people saw the Chinese immigrants who came to the United States as the SARS carriers and would spread it across the United States, making the community separate from the Asian community.

This idea was compounded due to the recorded history of Chinese immigrants being infected with TB in the 1990s, and the association of being an immigrant and poor meant that one could not afford healthcare (Eichelberger, 2007). During SARS, these assumptions or perceptions of Asians created a situation of 'othering' through prejudice and discrimination. Othering is when "individuals and groups may project the risk of infection and death onto an "other" in order to reduce the powerlessness experienced during a deadly epidemic" (Eichelberger, 2007, pg. 1285). When 'othering' occurs, those stigmatized are looked down upon, and there may be severe consequences for the communities. The disease no longer looked like a scientific issue of infection and transmission, but rather it takes a form or "moralizing metaphors of cultural superiority to locate risk and responsibility among marginalized populations" (Eichelberger, 2007, pg. 1285). The moralizing metaphors become a stigma for the Chinese communities, especially in New York's Chinatown.

In Canada, many faced similar treatment when SARS was announced in 2003. Asian Canadians faced a wave of stigma, discrimination and hate. In Toronto, Charmaine Leung conducted a study that examined what they faced during the SARS pandemic. The information gathered was through interviews and focus groups with volunteers that responded to the invitations sent out through postings by community organizations, electronic

forums and word of mouth (Leung, 2008). Her study is a part of a report that the Chinese Canadian National Council and Solutions Research created in response to the discrimination. The findings that Leung (2008) found depict stigma in every aspect of life. The first encounter of stigma described is in public, where people on public transport, the workplace, and school were stigmatized. Participants in her research report that on the subway in Toronto, coughing could clean a subway train as "a lot of people avoided Chinese people. I know there were a lot of experiences regarding the subway. If you sneeze or cough, you could empty the train!" (Leung, 2008, pg. 137) When this happened, many Asians felt

> "infuriated that if it was a white person, people felt safe. And if it was an Asian person, they would be seen as filthy and diseased... it felt like white people had good coughs, good lungs, good breath and Asians, especially Chinese people, looked hunched over, diseased, dirty, and unsophisticated. This is how I felt like people were being seen" (Leung, 2008, pg. 137).

In the workplace, people were avoiding Chinese people and making inappropriate comments such as "As far as I am concerned, the whole community should be locked up," or "I think China was making bioweapons and SARS is just one virus that escaped" (Leung, 2008, pg. 138). In other working locations, heavily Asian populated jobs such as nursing and long-term caregivers saw more stigma and discrimination due to their work and race. Participants reported that they felt isolated since people did not want to come in contact with them to the point where "people didn't even want to drive past the hospital! Taxi drivers wouldn't stop at the hospital entrance and dropped us off a distance from it" (Leung, 2008, pg.143).

The workplace was not the only place that people felt stigmatized at schools. Many schoolchildren face discrimination from their own teachers. One person reported that when they were picking up their child that the teacher informed them that specific foods would be allowed that they could not share, and other participants responded that they did not want to enroll their child into school until after the pandemic because they feared it would be too difficult to handle (Leung, 2008).

The impact on Toronto's Chinatown economy faced enormous losses due to people avoiding the area. During the SARS Pandemic, "restaurants in the area reported a drop of 60-80% during the SARS crisis and for several weeks thereafter" (Ali. 2008, pg. 53). Leung (2008) reports that income that was lost from businesses ranged from 40% to 80% and that public funding never reached the businesses and organizations (Leung 2008). In addition to small businesses losing income, many Asians were let go from jobs without just cause. There were cases where "many service workers who were laid off from restaurants, hotels and other service industries were left without adequate compensation...in many cases, poorly enforced labour laws, coupled with a lack of compensation, left many workers in desperate situations" (Leung, 2008, pg.141-142). In-home caregivers that came from the Philippines were also heavily discriminated against as many of them were "dismissed as if they were already

carriers of the disease. Employees were most concerned with the elderly or children in the family and yet showed little concern for their employees" (Leung, 2008, pg. 145).

Health Practitioner Stigma

Judy Yuen-man Siu (2008) conducted a study that used "a qualitative approach using anthropological and ethnographic study methods including participant observation and semi structured interviews" (pg. 730). The people interviewed were selected if they were a SARS victim. The research began with an observation period of 200 participants, and of those, 30 were selected for an interview (Siu, 2008). The research found that 100% of the participants interviewed found that their doctors were often "doubtful and skeptical about their suffering... hence these participants became the subjects of stigmatization under biomedical hegemony" (Siu. 2008, 732). Medical Hegemony is "the process by which capitalist assumptions, concepts and values come to permeate medical diagnosis and treatment" (Baer et al., 1944 pg. 14) and is displayed in the doctor's stigmatization because it is "stressing the need for the patient to comply with a social superior's or expert's judgement. One of the participants stated that "doctors often do not believe my uncomfortable feelings… and would blame me by saying that 'it's all in my head,' and 'if I try, then I should be able to overcome,' while another stated that "I felt very agitated because I am suffering from physical pain, but the doctors just believed that I have gone crazy" (Siu, 2008, pg. 732). The stigma for many patients that were recovering came from the doctors and caretakers that were supposed to take care of them after surviving a devastating ordeal. Siu (2008) states that the reason why doctors and caretakers stigmatized the recovering patients was that doctors:

> "followed the capitalist assumptions and values of Hong Kong society. As the participants were still unable to resume work and had to depend on government monetary subsidies such as the SARS Trust Fund to support their living expenses, they failed to fulfill the social norms and expectations of being self-sufficient in Hong Kong society." (pg.733)

Table 3 SARS/COVID-19 Stigma Summary

	Where Stigma Occurs	**Stigmatizer**	**Who is Stigmatized**	**Consequences**
Public Stigma	In the general community of villages and cities. As well as treatment centres, medical facilities, doctor's offices, etc.	The general public, family members, co-workers	Men and women that have contracted SARS	People who had SARS are treated differently, and that the public rejected many. Misconceptions about Asian communities, especially the

				Chinese community, rose as the public targeted them in public places.
Health Practitioner Stigma	Treatment centres, Medical facilities, doctor's offices, etc.	Health Care Workers such as doctors, dentists, nurses etc.	Men and women that have contracted HIV/AIDS	Medical professionals that did check-ups on SARS patients after they recovered dismissed their symptoms after they recovered. Often patients that complained of complications after recovering from SARS were not believed or dismissed.

In SARS there is a significant change of the different forms of stigma that are recorded through interviews and research. In SARS the research has only produced evidence of two forms of stigma. However, this does not mean that the other forms of stigma do not exist. Simply it means that they have not been formally recorded in academic research. Other reasons why other forms of stigma have not been recorded could be due to the duration of SARS which was significantly less than the other two infectious diseases. SARS appeared and disappeared in a time span of around six months. When it comes to Self stigma there may be some cases that are not recorded or have not been formally documented. People could have internalized the stigma, but nobody has ever actually researched this area. Other forms of stigma such as label avoidance, perceived stigma, stigma by association and structural stigma may not have been found due to the time SARS was active for. Many people that were infected with SARS sought medical help, and in the example above with Health Practitioner Stigma, they were rejected from medical help. As such label avoidance is not seen. For stigma by association or perceived stigma it is possible to explore the issue that Lee et al. (2008) raised where an entire residence building was stigmatized due to the impact of SARS on the residents in that building. There is a bit of evidence that stigma by association could have happened since people that lived in Amoy Gardens were often stigmatized because of their relation to the residence. For future research it will be important to see if other articles have been produced surrounding the other forms of stigma or possibly conducting research to fill the gap in the academic world.

De-Stigmatization Campaigns

As mentioned in the section above, there were many issues with people being stigmatized during the SARS outbreak due to their race and where they lived. Even after SARS was over, there were still such issues that affected many people. One of the major actions that were taken to help de-stigmatize SARS was in the United States where the " National Center for Infectious Diseases (NCID) at the Centers for Disease Control and Prevention (CDC) formed a 14-member, multidisciplinary NCID/SARS Community Outreach Team as part of its emergency response to the global SARS outbreak" (Pearson et al., 2004, pg.359). Pearson et al. (2004) conducted a study of the NCID's response and recorded the gathered results.

The NCID Outreach team began during the first three weeks of April 2003. It was tasked to develop an intervention that would be unique to the Asian American communities that would help promote "community understanding of the facts related to the transmission and prevention of SARS, contribute to the strengthening of community resiliency and capacity to mitigate fear, stigmatization, and discrimination; and encourage appropriate health-seeking behaviours for those who may have been exposed to SARS and were experiencing early symptoms" (Pearson et al., 2004, pg.359). The outreach team collected data from group discussions with key stakeholders, CDC Public response data, Asian language newspapers, internet sites, polling, community visits, panel discussions, medical interviews, and state and regional minority health liaison, which led to the development of relationships with Asian American communities. There was also the determination of new strategies to effectively collect data in the future based on the discussions conducted (Pearson et al., 2004).

The data gathering results allowed the Community Outreach team to identify specific methods of de-stigmatization of SARS. From the interviews, they saw that there was a need to:

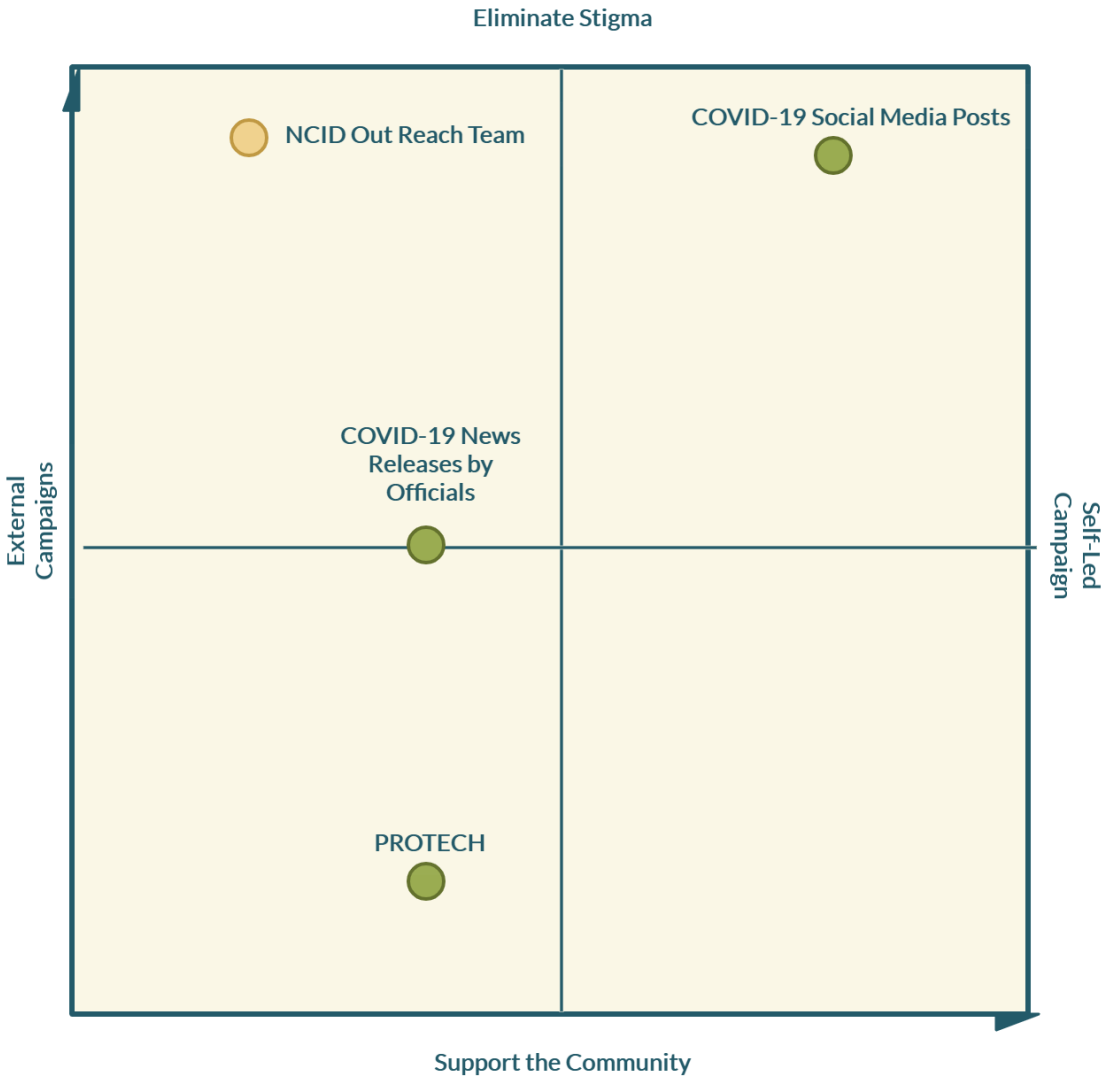
> "develop simple, tailored SARS prevention messages, develop SARS information materials in various Asian languages, disseminate SARS information through multiple and culturally appropriate channels, including (but not limited to) community visits, town hall meetings, and health education and communication channels to complement mass media messages, establish partnerships with local Asian-American community–based organizations to educate the community; and ensure that CDC would continue to provide leadership and coordination in preventing and controlling SARS" (Pearson et al. 2004 pg.360).

As a result, the CDC carried out three actions to help de-stigmatization, which were to advise SARS emergency response teams on reducing stigma in their communications, developing culturally tailored health education materials, conducting community visits, and discussing and media interviews to help curb negative behaviour. The CDC was able to

advise the response teams to reduce stigma in their communications by ensuring that the response team's messaging focused on the virus and the behavioural risk factors instead of the groups of people (Pearson et al., 2004). The culturally tailored education materials were provided not only in English. However, they were accurately and professionally translated into traditional Chinese, simplified Chinese, Korean, Vietnamese, Japanese, French and Spanish, which allowed for the dissemination of information to different cultural groups across the country. (Pearson et al., 2004). Since scientific information changed so quickly and the disease was rapidly evolving, the CDC response team worked to "identify priority documents for translation and ensure Asian-language translation for web and print products tailored to the Asian-American community" (Pearson et al., 2004 pg. 361). The information that was sent out in different languages was to inform people about how the risk of SARS was low, severe cases of SARS were uncommon, and there were no deaths in the United States, prevention measures were like any other viral diseases, and there was no evidence of community spread (Pearson et al. 2004). With such information beginning to be translated, the stigma is lowered since more people can access valid and verified information based on facts and is from a credible source.

The results of such actions found that providing targeted health educational materials and community field visits allowed for the dispelling of misconceptions, myths and rumours while also bringing the community together to develop better resiliency (Pearson et al., 2004). It also allowed the CDC to reassure Asian communities as the CDC field visits found more stigmatization within the community than outside. This discovery of stigmatization within the community was through open discussion with members of the community and informal data gathering. Such discussion also revealed that people that relied on traditional herbal doctors or pharmacies were less likely to seek public health officials (Pearson et al., 2004). In the example of SARS, the method of de-stigmatization was to provide accurate information to the community within and around the stigmatized people. This was done by giving access to such information in languages that people could understand, identifying trusted information sources, and conducting community visits to inform community leaders and members of facts while debunking myths and rumours. SARS is also very unique due to the level of media coverage of the disease over a brief period. While SARS affected different countries worldwide, China had the largest number of cases, but the United States deployed the most resources to combat stigma. The United States responded to SARS by activating their Emergency Operations Centre to provide constant response and coordination, deploy over 800 staff domestically and around the world to support the SARS response, conducted extensive laboratory testing to identify the cause of the disease and finally created a system to distribute health notices and alerts to travellers who were exposed to SARS (CDC, 2017).

Figure 1.3. - The SARS and COVID-19 De-stigma chart shows where the CDC's actions and the present actions for COVID-19 are seen in relation to each other.



Future Interventions for De-stigmatization

The future research for SARS has continued but not specifically in responding to SARS. Since SARS only lasted a short period, the research done is for other infectious diseases such as COVID-19. Lessons learned during SARS have been referenced and used by people responding to COVID-19. The reason being is that SARS is unique compared to the other infectious diseases that are being examined in this paper. The SARS duration is much shorter than the other infectious diseases being examined, which meant that there was not much discussion of developing future research. The illness was only around for a short period, and while there have been many other diseases that were similar to SARS, there has not been a global pandemic of the magnitude of SARS that has happened until COVID-19. However, the research that has been done has suggested future reference points to explore further should another incident as SARS occurs. For example, based on the CDC's research in Pearson et al.'s (2008) study, it was determined that the public health care system and the

professionals that work in it must be ready to balance the need to protect people with acceptable practices while also preventing fear, stigma and discrimination to happen to specific parts of the population. This was addressed with the community visits, targeted messaging with translations, and the messaging on the infectious disease instead of the people of the country from which it came. The fear aspect of an epidemic or pandemic will need to be addressed along with the infectious disease's physical threat.

Other areas of research that have been outlined by Eichelberger (2007) is that research needs to be paying attention to the " ways in which people are othered within a community, not just externally" (pg.1294) as well as ensuring that we "vigorously criticize othering in the media and public health statements, and do so to an audience beyond the social sciences" (pg. 1294) and finally that the" studies of stigmatization need to be integrated with those of cultural constructions of disease to understand more fully how people perceive a disease, their risk, and the appropriate measures for prevention" (pg. 1294). This is especially important to the future of studying de-stigmatization campaigns as we will need to examine how power within different elements of society transfers from one set of people to another and how the power of media and the community can create the perception that a particular person has a lower health status and a higher risk of disease contraction all because of their race or area of residence.

Furthermore, communication is critical as the media plays an essential role in disseminating information and reporting legitimate facts. The media can control or influence the way people perceive others and create conflict where conflict may not exist. One example of this in SARS was that "mainstream Canadian print media contributed to the racialization of SARS and generation of public hysteria. Despite its relatively low death rate, the SARS outbreak was repeatedly compared to the Spanish Influenza pandemic of 1918 to 1919, which killed at least 20 million people" (Leung, 2008, pg.147). This representation created more panic than needed and gave a skewed perspective of what was the reality. This comparison was one of the reasons why many people avoided labelling COVID as the Wuhan Virus as it would give the same reaction as it did with SARS. Finally, it is vital to understand that stigmatizing a particular population will hinder the ability to tackle the disease with stigma.

Stigma, or as Eichelberger (2007) describes 'othering,' can hinder the ability to control disease because many may reject public health instructions, and it may create a false sense of security for others. The final aspect that is suggested for future research is globalization and its impact on a disease. Now that the world can connect, so can infectious diseases, which should be considered when other epidemics or pandemics occur. It can affect the rate of spread and the severity of the disease (Eichelberger, 2007). Eichelberger (2007) is describing how globalization has allowed the world to connect and bring people together, but at the same time, the same networks that connect us will also connect the infectious disease to us, and we must ensure that research is put into how globalization can spread an infectious disease. The idea of othering is also reflected in the need not to name COVID-19 the Wuhan virus as it creates this situation where an entire race is separated from society based on misconceptions and false information. By not naming it the Wuhan Virus and not comparing

it to the Spanish Flu, the media was able to help avoid a situation where the Chinese population and the people that lived in Wuhan, China were “othered”

In Leung (2008), the report that is developed comes with a series of recommendations on improving the response to the next pandemic. She makes seven recommendations, which are similar to the actions that were taken by the CDC. One of the biggest factors with stigma in the media and a recommendation that is made is to have mainstream media ``reduce racial stereotyping in its content, including the establishment of community editorial boards or regular meetings with members of racialized communities for feedback and information-sharing” (Leung, 2008, pg. 148). Other actions discussed are to have comprehensive plans in all levels of government to fight racism and discrimination, which include public crisis response plans that include analysis and targeted response to stereotyping and racism (Leung, 2008). Finally, she suggests that racialized communities should be included in health research and that public health authorities should have information available in different languages to reach as many people as possible.

Discussion

The research that has been conducted on three different infectious diseases which are Tuberculosis, HIV/AIDS and SARS, was to understand what stigma was associated with each of these diseases, how they affected people and communities, the actions that were taken to de-stigmatize the people with the infectious diseases and how the lessons learned from previous campaigns and initiatives would be able to help fight the stigma of future infectious diseases like COVID-19. This paper's structure begins with a background that explains the origins of stigma, the research that has already been completed, the different types of stigma, the stigmatizers and their role in creating stigma, and finally, an introduction of what de-stigmatizing campaigns and initiatives are. After the research dives deeper into the three infectious diseases, which are Tuberculosis, HIV/AIDS and SARS, each of the chapters will provide a background of the disease, the effects it has on people and finally, the de-stigmatization campaigns and initiatives that are being used to help combat stigma. Finally, the chapters explore the future recommendations or research suggested to help create more effective interventions for de-stigmatization for each of the infectious diseases.

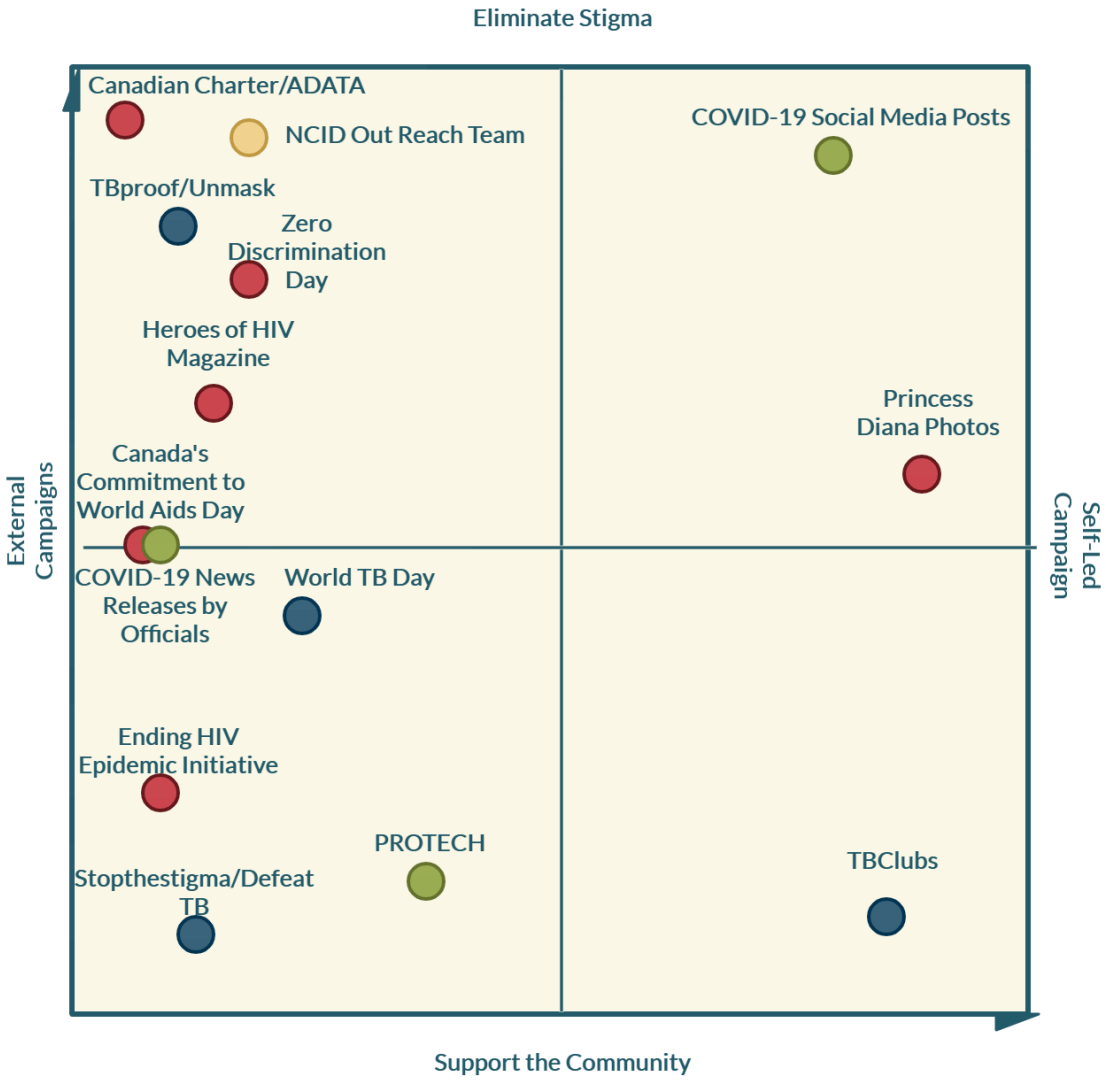
Throughout the research of three different infectious diseases, it was shown that specific types of stigma were perpetuated more often compared to others in the articles that were examined. The specific types of stigma that have been identified in the background chapter came from Grappone (2020), and she identified seven types of stigma that somebody could face. Throughout all three infectious diseases, public stigma is a common theme in all three while self-stigma and label avoidance show up in TB and HIV/AIDS and Health practitioner stigma shows up one in HIV/AIDS. Throughout the paper, structural stigma does not show up in the research that has been examined. One reason why structural stigma is not reported as much could be due to the progressive society we live in, and laws or policies are heavily scrutinized by human rights and oversight organizations or by a sampling bias at the papers examined.

In this case, public stigma is where people who have or have had the infectious disease are stigmatized by the public through misconceptions, discrimination, and prejudice. On the other hand, self-stigma and label avoidance are a form of stigma that the person with the infectious disease inflict on themselves due to what people have said towards them or the perception of what people will say. Self-stigma in TB and HIV/AIDS has caused people to have lower self-esteem, depression, eating disorders, self-isolation and other mental health illnesses. Label avoidance in TB and HIV/AIDS has caused people to avoid treatment by either not seeing a doctor or specialist or not adhering to the medication regime as they do not want to have a label of a person who is infect imposed on them by the people that see them enter a medical clinic or take medication. Health practitioner stigma shows up in the research for HIV/AIDS and SARS. Health Practitioner stigma in HIV/AIDS and SARS takes form when doctors, medical staff and other medical professionals treat people who have HIV/AIDS and SARS differently because of their illness. Examples of this could be double

gloving when doing dentistry work on an HIV/AIDS patient or dismissing a patient's symptoms when they tell the doctor they had SARS. Stigma by association and perceived stigma only shows up in the articles discussing HIV/AIDS. Stigma by association when dealing with HIV/AIDS is seen when people who are helping or are with a person who is diagnosed with HIV/AIDS are assumed to have HIV/AIDS as well, by the general public. Perceived stigma occurs when the individual with HIV/AIDS believes that people stigmatize them due to the illness. This form of stigma can take the form of believing that people are talking poorly of you because you have HIV/AIDS, or it could be that people avoid you due to HIV/AIDS when in reality it may not be true.

Many of the authors that have been examined throughout the paper recommend that public education and the elimination of stigma while also supporting the community are vital for de-stigmatization. Throughout the paper, many different actions for de-stigmatization or actions that contribute to de-stigmatization have been identified and plotted on the de-stigmatization chart seen in figure 1.3. Figure 1.3 has plotted all the actions that have been examined in the three infectious diseases and have been able to demonstrate that the key findings from the paper have been discovered. In Figure 1.3, different colours are being used to describe the different infectious diseases. Dark blue is used for the campaigns or initiatives relating to TB, red are used for those associated with HIV/AIDS, yellow for those associated with SARS and green for COVID-19.

Figure 1.4 All De-stigmatization initiatives



First and foremost, it shows that many actions that have been taken target education and community outreach. Based on the image above, there needs to be further research into Quadrant I and IV to unearth more actions that come from grassroots level communities. The figure above shows that many actions have been taken to support those that have been stigmatized and the need to produce a social media presence for future actions like what many people did for COVID-19. Finally, the actions recorded in figure 1.4 also support that there has been a lack of historical campaigns, actions or initiatives that help with de-stigmatization in this research. Many of the plotted dots are modern or after the 1950s.

While Tuberculosis, HIV/AIDS and SARS are three very different infectious diseases, through examining them and the initiatives that were done to de-stigmatize them, there are commonalities between them. As such, in this section, those commonalities will be discussed starting with the different types of stigma seen in the sources gathered. The discussion will continue to show how de-stigmatization has created at least observations that can be taken

away from the research. The six observations identified include: 1) the importance of education and the changing of perceptions of people; 2) the importance of community outreach; 3) the need for more research into grassroots campaigns that eliminate stigma and support the community which is Quadrant I and IV of the de-stigmatization chart; 4) the need to provide social support to victims of stigmatization through local initiatives; 5) the use of social media for the future; and 6)lack of de-stigmatization campaigns in the literature that are historical.

Observation 1.The Importance of Education

Based on the number of campaigns and initiatives mapped out on the chart, it can be seen that the majority fall within quadrant II and III, which are the external campaigns and initiatives that support the community and end stigma. When referring to external campaigns, the meaning is that the campaigns or initiatives come from an external organization from the community, such as a government department, a not-for-profit organization or a non-governmental organization. Grassroots campaigns and initiatives are defined as those that are self-led and raised from the community. This can be in the form of social media campaigns that people from a local community do, or it could be an awareness campaign done at a school or community group. While most campaigns or initiatives were done by external organizations, all of them had the commonality of public education. The public education that was used targeted different areas of stigma. Some raised awareness of the disease and the ability to treat it, as seen in the campaigns associated with World AIDS Day, while others were used to educate the public and break the stigma, as demonstrated in the Unmask campaigns for TB. As such, it can be said that education is one of the main methods used, and the changing of perceptions is important when trying to de-stigmatize an infectious disease. Courtwright and Turner (2010), Daftary et al. (2017) and Brown et al. (2003) have a notion that education and collective storytelling of the experiences of those with infectious disease is necessary for the de-stigmatization of infectious disease. As such, public education is an important aspect in the fight for de-stigmatization.

This notion is seen recently with the City of Toronto's Anti-East Asian Racism web page in response to COVID-19. The City of Toronto has posted stories about racism, information about the effects of racism and has engaged the public by using social media to educate the general public. Education can be done through community outreach and social media, as those are some of the most effective ways of doing so. Regardless of the form, it takes whether it is a government-funded or privately funded campaign or initiative or one that has come from community members educating their community, public education is one of the best tools that can be used to de-stigmatize.

One of the reasons why education is so important for de-stigmatization is because stigma towards certain people only appears when someone else's perception of them makes them seem different. As such, education can help correct such misconceptions. For example, with HIV/AIDS, there was a misconception about how it was spread, and many people were

afraid that having contact with an HIV/AIDS positive person through a handshake would transmit the disease. Through proper education and simple actions like what Princess Diana did to de-stigmatize HIV/AIDS patients, many now know that HIV/AIDS is only transmitted through bodily fluids. Another example is TB, where this research showed that many people are stigmatized since they have TB, but those that stigmatize are not aware that TB is a treatable illness that can be cured through the intake of proper medicine. Quadrant II and III have recorded that most initiatives use education to support those being stigmatized and help reduce stigma.

Observation 2. Community Outreach

The next lesson learned from the three infectious diseases is the need for community outreach. It has shown to be effective in supporting the community and providing education for those who may have misinformation or may have a notion to stigmatize. During SARS, the CDC was able to distribute information and collect data to help the Chinese community. With this lesson, it was identified that being able to talk with community leaders, citizens, and those in the community provided officials' ability to target specific issues that were arising. At the same time, community outreach has been able to help with de-stigmatization for infectious diseases as many campaigns and initiatives can reach both the stigmatized and those that are stigmatizing. For those that are stigmatized, it supports them to see a champion breaking stigma, which is shown by the example of Princess Diana and HIV/AIDS patients and the Heroes of HIV magazine by the Vangardist. Other examples of this could be the Unmask campaign for TB, where community groups tried to create awareness and reduce the stigma of wearing a mask, limiting transmission in TB patients. The research supports the idea that public outreach is a successful method to help the stigmatized community while also changing perceptions. The community outreach portion is very much connected to the education portion.

Furthermore, the research supports the notion that when external and grassroots campaigns and initiatives connect with the community and build a sense of dialogue and understanding, progress can be made. However, it may be necessary to take it one step further where the stigmatizers and those being stigmatized can have a dialogue where both sides can express their viewpoint to understand where each other is coming from. It must be more than a conversation or a discussion but rather a time to share perceptions and understanding. Once that can be done, and people can develop informed opinions, the stigma may be reduced, and support may increase. Lessons or information that the stigmatized community can learn from the stigmatizers could be where the misconceptions come from, why they are stigmatizing others, what might be needed to properly educate the stigmatizers and finally ways of addressing the misconceptions that produce stigma. It may also reveal the emotions and feelings that stigmatizers feel when they are stigmatizing others. It could be a response to a genuine fear of the person or a hatred towards them.

Observation 3. Quadrant I & IV Research

As seen in figure 2.4, most of the campaigns and initiatives that have been recorded by this scoping review are in Quadrant II and III. Quadrant I and IV are lacking in the academic articles. Such actions were partially mentioned in grey literature and it is possible that such actions were not captured in this review due to bias or insufficient research. As stated above, external campaigns are those that are created by another organization, while grassroots campaigns are those that come from the community. Understanding what the community is doing is important since many of their ideas can target local problems. It can also be an opportunity for researchers and public health officials to see how they can gain public trust and enact initiatives and campaigns to help with de-stigmatization. Education and community outreach are two very important aspects as pointed out above, but further research into what grassroots campaigns or initiatives are being done by the community, such as church groups or schools, can lead to inspiration to help others such as TB Clubs, which help a stigmatized community overcome the stigma and become healthy. Furthermore, when further research is completed to look at these two areas, better initiatives and campaigns can be developed for future use. It can act to address community issues early and help public health officials be aware of issues while also creating public trust and support local initiatives done by the community.

An explanation for this is that the research primarily focuses on what is documented in public articles and in public archives, which means smaller campaigns may not be on the radar of some researchers writing their scholarly work. Many grassroots initiatives may not be recorded, so other resources such as grey literature may be needed to map out the full extent of what is being done.

Observations 4. Support for Those Stigmatized

Another significant finding that is important when addressing stigma, is who it affects. The different social classes worldwide who have access to very different levels of assistance and resources will be affected by stigma differently. In all three infectious diseases, the population that was hit the hardest were those that were living in poverty or had a lower income. Access to resources plays a major role in ensuring that people are not stigmatized. For example, in the case of TB, those that can get treatment sooner may be able to live a long and happy life after their treatment.

In contrast, those that cannot afford the drugs required to cure TB may suffer or may experience a higher mortality rate than those that can have access to resources. To properly address stigma, it is important to understand that the economic situation and access to resources play a large part. For example, TB is usually associated with the poor, but that is only because they do not have access to medication and proper living spaces that allow for

proper sanitation. The importance of using dialogue to capture the full picture is important in order to develop facts instead of misinformation. There is a need to support those that are affected by infectious diseases because without such support. We risk seeing more not adhering to medical treatment, more people facing stigma alone, and most of all, a larger burden on a public health system that already has many people that require treatment. It is possible to look at the idea of TB clubs and equate that to Alcoholic Anonymous (AA) and see the benefit of supporting a community to overcome a certain obstacle. While infectious diseases are not the same as addiction, the concept of support can be referenced. Much like how a sponsor may support somebody to be sober, a community or a community leader can support those that have or had TB, HIV/AIDS or other infectious diseases, in the same way, to adhere to medical treatment, provide emotional and physical support for those in need and be a place where those affected by stigma due to infectious diseases can seek help and comfort.

Observations 5. Historical Campaigns or A Lack Thereof

The research also showed an interesting notion that de-stigmatization campaigns and initiatives are a recent phenomenon. Historically speaking, there is not much-recorded information of campaigns or initiatives or even actions that people did to de-stigmatize infectious disease. What is meant by this is for infectious diseases such as TB or HIV/AIDS, which have been around for decades or even centuries, the actions needed to de-stigmatize the disease are only seen in modern times, starting with the 1900s with HIV/AIDS. It is quite possible that there could have been actions taken to de-stigmatize these infectious diseases but were not recorded in academic journals or scholarly work. It is possible that such campaigns may have been recorded in local grey literature, such as a newspaper or flyer that was used by the local community.

In addition to observing that many de-stigmatization campaigns are relatively modern, there is a possibility that history can answer why de-stigmatization campaigns are only a ‘recent’ phenomenon. The reason could be the lack of understanding of the diseases. Science and modern technology have been able to help discover what caused these diseases and ways to prevent them from spreading. However, before this understanding, the concept of diseases was seen as an ‘act of God’ or a punishment for defying a sovereign (Barberis et al., 2017). As a result, the society that was developed only saw disease as a punishment and did not go further. As we progress and learn about these infectious diseases, more is explained, and people become educated about the disease and their perception changes over time. This could explain why de-stigmatization campaigns and initiatives are only seen when technological advances were made.

Observation 6. Social Media

In addition to all the educational materials needed and the further research that should be conducted, the exploration of how to effectively use social media for public health initiatives such as de-stigmatization infectious disease can change how we respond to stigma. Social media can connect with people faster and provide accurate information if it comes from a legitimate source. This use of social media is a positive and a negative tool since legitimate information can be distributed but also false or stigmatizing information can also be distributed by members of the public and those of higher office. As demonstrated by the research on TB, HIV/AIDS and SARS, the community outreach combined with targeted education and support allowed for de-stigmatization. It may be possible to prevent stigma before it happens by using social media properly. For example, if on World TB Day or World AIDS day, organizations and people spread awareness about infectious disease stigma, it could bring awareness to the community. The link between awareness and stigma goes back to education. Being aware of how a disease works instead of misconceptions can help develop a community that understands what the needs of those that are stigmatized are and can also inspire others to take action. Awareness and good education help reduce stigma by providing factual information, and in the case of social media, it provides information in an instance which is also convenient for many people. This idea or concept is not new. It has been seen already with campaigns and organizations such as '#BellLetstalkday' for mental health(Bell., 2020). This campaign is held annually and is hosted by Bell Canada. It aims to use social media such as Snapchat, Twitter, Facebook, Instagram and other platforms to promote awareness for mental health and destigmatize those who have mental health issues. The same can be done for infectious diseases, and with today's technology and connectivity, the possibility is limitless as to how we raise awareness on the internet. This initiative is proactive by getting people to talk about mental health, so people do not feel that sense of stigma.

COVID-19

Currently, with COVID-19 or SARS-CoV-2, we see that many of the same issues have arisen that the three infectious have seen as well. SARS however is more relatable to COVID-19 as the stigma of the disease have been directed towards Chinese people again. There are observations from the other two infectious disease that can be used for future initiatives and planning but SARS provides the most recent and is best connected to COVID-19. During the COVID-19 pandemic, there have been reports from the media that stigma has still been placed on the Asian Communities. Compared to the 2003 SARS Pandemic, COVID-19 has seen a lot more stigma being put on the Asian Community due to the accessibility of social media and instant messaging. For example, Larry Heng from the National Post reported on January 30, 2020, that CTV investigative reporter Peter Akman "tweeted a photo of him next to an Asian barber wearing a medical mask. "Hopefully, ALL I got today is a haircut," he wrote in the tweet. There have been other tweets like "#coronarvirus Canada is gonna get fucked by this virus have you seen university of waterloo" (Heng, 2020). One term that had been used in 2003 and again in 2020 is the "yellow peril," which is referring to the Asian Community. Evelyn Kwong wrote in the Toronto Star on January 23, 2020, that the "Yellow Peril" had returned, which was referring to how society saw the Asian Population. The Yellow Peril stigmatized Asians as "unsanitary, lower-class, and alien" (Kwong, 2020, n,p). The term did not originate during the SARS pandemic in 2003 but in 1885, when Canada imposed the Chinese Head tax on immigrating Chinese people (Kwong, 2020). Even today, Kwong (2020) reports that "the lessons we had hoped to learn haven't been resolved and are rather amplified by our digital world. We, like Asians, are still being asked if we eat dogs and bats, and now more so than ever on social media." The stigma is still prevalent during COVID-19.

While the stigma of the Asian Community has re-emerged, the response to such stigma has also re-emerged but quicker. Such stigma is transferred from a disease to an ethnic group in the same way social media can help with de-stigmatization. When misinformation about the disease is constantly shown, people may wrongfully associate it with an ethnic group rather than an individual. Since COVID-19 originated from Wuhan, China, many people associate Chinese or Asian people with such disease based on their appearance. This association is a form of stigma as it is a negative stereotype and has discriminating behaviour. While stigma can describe the intolerance shown to Asian people, another word may be scapegoating as some blame the Asian population for the disease. But one may argue that Asians are being used as a scapegoat due to the stereotyping that people do and the discrimination and prejudice that occurs with the stigma that people project onto Asians. Social media sites, bloggers, politicians and the common person have reacted faster and help de-stigmatize COVID-19. One of the largest impact areas was the economic impact again, where restaurants and Chinatowns suffered as people avoided them. Many people immediately took action to help small restaurants, such as His Worship, Mayor Frank Scarpitti of Markham, went to the noodle store Wuhan 1950 and posted positive comments about the restaurant hoping that people would still come in and eat (Miller, 2020). Her

Worship Mayor Bonnie Crombie and some city councillors did the same when they visited restaurants and posted pictures on their Twitter accounts (Kan, 2020).

Other examples on social media were from the residents who have been posting positive messages and encouraging people to eat at Asian restaurants. On the official side, statements have been released by The Right Honourable Prime Minister Justin Trudeau and Dr. Theresa Tam condemning the racism, discrimination, stigma and stereotypes that many Asian Canadians are experiencing (Jones, 2020; Flanagan, 2020). Academic institutions are also developing methods to help de-stigmatization, such as Ryerson University. Together with her research partners, Josephine Wong of Ryerson University created the Pandemic Rapid-response Optimization To Enhance Community-Resilience and Health (PROTECH). This platform has a COVID-19 info Hub that provides accurate and current information while also providing information on coping with fear and anxiety (Leach, 2020). Another feature of PROTECH is online group training with video conferencing or live chat that helps reduce stigma and stress while promoting resilience among affected groups (Leach, 2020). The platform is also accessible in both English and Chinese languages. This design is quite similar to what the CDC did in the United States when SARS broke out.

Most of the lessons learned during the examination of three infectious diseases have been shown or identified during the COVID-19 pandemic. The first aspect of education to help de-stigmatization is seen when Governments, Health Organizations and community members share valid and credible information among the community in order to properly inform themselves and those around them. For example, the PROTECH platform allows for information to be distributed to community members in their language, which allows for the information to reach more people. Furthermore, the City of Toronto's Anti-East Asian Racism web page in response to COVID-19 is another example that shows how education is being used to de-stigmatize COVID-19.

Community Outreach during COVID-19 was not only for the Asian community. Many people began to reach out to others in their local neighbourhoods and areas to see if they could help in any way. Volunteer organizations set up services that helped elderly people get groceries or people who needed medical supplies were given some help. This is an important service as it helps the elderly avoid being stigmatized by the general public. This action also binds the community together which is important when facing stigma from other people. Services such as mental health support got virtual makeovers to allow people to access them from the safety of their own homes. Communities have been gathered together and are using modern technology to support each other through virtual support groups, and many innovations have helped those affected by COVID-19 to get the resources they need like food or mental health support through apps or virtual meetings. This innovation is also an example of how the response to COVID-19 has begun to use social media more effectively. We saw community members and organizations such as local governments or NGOs help de-stigmatize the Asian community by encouraging the public that it is safe to eat at Asian restaurants. Furthermore, the usage of social media has been utilized by health officials and governments to spread factual and critical information surrounding COVID-19.

The final lesson learned from the paper is the lack of examples in quadrant I and IV, where few grassroots actions were recorded. During COVID-19, however, a small change was seen where grey literature was able to help fill in the gaps that were missing in this quadrant. Things such as social media posts from the community and records of local people doing local actions have been picked up by news outlets and broadcasted for people to know. Two things may cause this phenomenon. The first is the accessibility of technology, and the second is globalization. Today, social media platforms such as Twitter, Snapchat, Instagram, Facebook and many more allow people to record and send information very quickly to people within their network. This is compounded by the fact that people worldwide can communicate with each other very quickly and simply. The need to know what is happening on the other side of the world also plays a role in people knowing about local campaigns. Somebody posting in Toronto may have their content looked at by somebody in Japan or Egypt within a matter of seconds, which may get reported in local media or on local news sites.

The six observations that were gathered from the research also contributed to future research into these topics. The 2x2 chart seen in figure 1.4 and the utilization of seven different forms of stigma to analyze the research and the summary of the different de-stigmatization campaigns have all contributed to the progression of research when it comes to stigma and infectious diseases. With the 2x2 chart, future researchers can use it as a template to map out more actions found in other studies, but it can also be modified to analyze different actions differently. The chart allows other researchers to understand where this study has plotted each of the initiatives examined and can then continue filling the chart based on the information. While the chart may be modified, it may reveal a new pattern or new gaps that need to be further researched.

The utilization of the seven forms of stigma presented by Grappone (2020) has contributed to the progression of research by furthering the level of detail that stigma is looked at. This use of Grappone's (2020) system can quickly summarize the stigma that people have when they are infected with a specific infectious disease. This information can be used to deal with other infectious diseases by identifying what stigma people face. In return, better initiatives and actions can be taken to address these issues that are identified by the separation of different forms of stigma.

Finally, the six observations that have been discussed can help shape the future of de-stigmatization actions and initiatives and the research that is being conducted by future researchers. It is important to make a note of these six observations as they touch upon what is needed for the future of de-stigmatization, what is needed to ensure that when another infectious disease emerges or when an existing one re-emerges that the proper actions and resources are used to stop stigma as soon as possible. The lessons learned also show what tools can help with de-stigmatization and the gaps that have been identified, such as the examination of more grassroots actions and more examples of structural stigma. In conclusion, the six lessons that have been discussed can be applied to future infectious

disease and current ones to help with de-stigmatization. It has already been shown that the response to COVID-19 has used many of the lessons learned and that for future reference, the same lessons can be used. It is important to remember these lessons as new infectious diseases will continue to arise, and stigma is a large social issue that affects the entire community. Stigma creates a social divide and is a threat to public health as those that face stigma and stigmatization may hinder the process needed to respond to an infectious disease.

Overall, observations from other infectious diseases can provide answers and innovative solutions to the current issues that present during COVID-19 and future incidents that involve infectious diseases. A better understanding of what has been done before and what is currently done can help develop a level of benchmarking which this paper has done, and even though the list is not complete, it provides a snapshot of the actions that have been taken and the areas that can be improved with better campaigns, initiatives and research. In conclusion, while there are only six main observations, there are plenty of other observations to be gathered from this research, and as technology and human innovation grows and expands, so will the actions and initiatives that are done to de-stigmatize infectious diseases. The next infectious disease will come with its challenges and new lessons to be recorded, but previous lessons that have been taken into account, such as the ones highlighted in this paper, can help make it a bit easier to respond to the future as there will be a level of preparedness that is present.

Conclusion

Overall, in this research paper, three infectious diseases have been examined: tuberculosis, HIV/AIDS, and SARS. These infectious diseases have informed us of the stigma that people faced because a particular disease infects them. At the same time, the paper also revealed the actions that have been taken in order to de-stigmatize the same infectious diseases. Of these actions, six observations have been extrapolated, which were 1) the importance of education and the changing of perceptions of people; 2) the importance of community outreach; 3)the need for more research into grassroots campaigns that eliminate stigma and support the community which is Quadrant I and IV of the de-stigmatization chart; 4) supporting victims; 5) the use of social media for the future and 6)lack of de-stigmatization campaigns in the literature that are historical. Most of the six observations, if not all, have been reflected in the current response to COVID-19 by communities and organizations worldwide. It is necessary to understand that the observations, and the summary of the stigma recorded by this paper, can be used for future incidents and even existing ones.

Quite a bit of this research can record the actions done during the COVID-19 pandemic to understand what will work for the current society that we live in currently. The lesson learned for three different infectious diseases was that stigma will exist due to the misconceptions and biases people grew up with when they were younger. Somebody will inevitably meet someone that has a low opinion of them. However, the way that we address such issues through campaigns, initiatives and interventions that must be taken to de-stigmatize an infectious disease must have the ability to reach the people in the community and that the information being distributed must be accessible to everyone in a manner that they understand. We learned that de-stigmatization campaigns work and can lower stigma through education and breaking misconceptions, but at the same time, the research conducted revealed that there are gaps in the support that people need while being stigmatized. There also needs to be a more robust understanding of what the people can do to better their community, and if there are already such actions, more in-depth and more detailed research is needed to record such actions as this is where innovation is shown. People without any resources will find creative methods to achieve the objective, and some actions are worth using for the future

Stigma has developed from ancient times and has moved from a physical mark to a mark on people within a community or society. Stigma is heavily associated with different infectious diseases. However, the result of the stigma is generally the same as others may see people with an infectious disease as different and as a result, the quality of life for those seen as different deteriorates. At the same time, others see this and have acted to support and spread factual information about a stigmatized infectious disease. The research conducted on Tuberculosis, HIV/AIDS, SARS and COVID-19 has been able to give a snapshot of the impacts people face and the actions that people have done to help. In conclusion, it is crucial to recognize that stigma affects all areas of life and those community members and organizations have helped create change and awareness while providing support. The future

of de-stigmatization will need to address the misconceptions and biases that people have developed, and this scoping review provides the first steps to creating a definite movement.

Future Research

Based on the research at hand, a recommendation for future research would be to do a study where a stigmatizer and somebody that was stigmatized has dialogue and records the results. It may lead to a better understanding of what is needed in the future. This aspect of research deals with the community outreach portion but not in the sense of asking what a community needs for help but instead targeting the issue of a person that is stigmatizing others.

Another observation related to time is the actions recorded and the campaigns and initiatives that can be reviewed for a specific infectious disease. TB and HIV/AIDS have been around longer and are still ongoing, which is why more articles and examples were found as compared to SARS, where only a limited number were found and used. The only explanation that could be thought about is that the more time a disease lasts, the more actions can be taken. However, at the same time, one idea to think about for further research is if an infectious disease stops but another with similar circumstances appears within a short period to see if the general population reacts the same. An example of this is SARS and COVID-19. Both originated in China, and both had similar reactions to the public when it first began. The difference was that the people who experienced SARS were ready and able to react faster than what happened originally with SARS regarding responding to stigma.

Finally, for the future of infectious disease research and stigma, we may want to look at the intersectionality of different infectious diseases and how they can teach valuable lessons for the future. A holistic approach towards addressing stigma is needed, and one of these options is looking at how TB and HIV/AIDS can help with de-stigmatization. The fact that TB and HIV/AIDS have been associated with each other can create another research area on how these people can be helped through de-stigmatization. It may be considered that finding out how to tackle this issue can help with other infectious diseases associated with each other.

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