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Keeley LaRiviere
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**Surveying the Stigma: How the PLHIV Stigma Index acts as a validated
framework to measure healthcare discrimination and how it can be adapted
to quantify mental health stigma**

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Fall 2022

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Abstract

The PLHIV Stigma Index is an ongoing, international study conducted by and for people living with HIV to measure the stigmatization that people living with HIV experience. As a model that has been proven successful in translating to targeted advocacy campaigns, this paper theorizes on how this Stigma Index could be broadened to capture other aspects of healthcare discrimination. With a growing demand for mental health support and a critically underdeveloped mental healthcare framework, understanding the stigma and discrimination that exist for people living with depression is a good place to start. Using mixed methods analysis from existing literature and expert interviews, this study dives into the feasibility of and demand for the development a depression stigma analysis tool. Despite the large number of experimental design based metrics for this, there is a gap in the existing literature that lies in peer-to-peer qualitative analysis. This paper explores the existing model of the PLHIV Stigma Index, depression stigma, the comparison between depression and HIV, the need for a stigma analytical tool in mental health, the ways that the PLHIV Stigma Index could inform such a tool, and the key considerations of this kind of plan. Finally, tentative recommendations for future policy, advocacy and research are made.

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discrimination. The work that you do is changing the world for the better and I look forward to joining you in the near future.

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Introduction

The right to health is a human right outlined and protected in the Universal Declaration of Human Rights, as all people have the right to a standard of living adequate for the health and wellbeing of themselves and their families. Unfortunately, there are a variety of barriers that impede the ability of many people to access healthcare services and obtain their highest levels of mental and physical wellbeing. One of these barriers is stigmatization and discrimination in and out of healthcare settings. There are two relevant aspects to consider when discussing stigma and those are the external and internal manifestations. External, or social, stigma is defined as the harmful attitudes and behaviors that an individual or community will have towards/about a certain group of people. Internal, or self, stigma occurs when a person internalizes these stereotypes, leading to a negative self-image and loss of self-esteem [4,6,18].

In 2016, at the United Nations Political Declaration on Ending AIDS, there were reports of widespread stigmatization and discrimination that were connected to the legal and policy frameworks that continue to restrict the lives of people living with HIV (PLHIV) [8]. An example of bureaucratic blockage in another aspect healthcare due to stigma is how the median proportion of mental health funding in governmental budgeting globally is just 2% while approximately 11% of the global population has been diagnosed with a mental health disorder. The magnitude of this failure comes into perspective when it is understood that 1 in every 4 years lived with disability (YLD) internationally are caused by mental, neurological and substance abuse disorders. Right now, it's more important than ever to emphasize destigmatization advocacy to squash misconceptions about mental health. During the first year of the Covid-19 pandemic, rates of anxiety and depression went up by more than 25%. The increasing population in need of mental health services is putting a strain on the already

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underfunded mental health sector. It is necessary to bring more awareness to these issues not only because the right to mental well-being is a human right, but also because increasing mental health treatments has a 5:1 economic payoff based on estimated investment needs [23].

Advocacy is defined by GNP+(the Global Network of People Living with HIV) as an aim to raise awareness and bring social change [8]. Two of the primary factors contributing to mental health stigma are the widespread misinformation and ignorance regarding the issue. One study found depression stigma to be negatively correlated with knowledge on the condition, meaning that the less people knew about depression the more likely they were to hold stigmatizing views of people living with depression (PLD). That same study also noted that this stigma deters people from seeking treatment out of fear of being labeled as ‘psychotic’ [7]. This issue is everywhere, in high income countries where healthcare systems are more robust than those in low to middle income countries, only one third of PLD receive formal treatment [23]. It is imperative that as a global society we increase mental health awareness in order to shut down the damaging misinformation fueling these stigmas and healthcare gaps.

Depression and anxiety are the two most common mental conditions among the general population [23]. For the purposes of this paper, the focus will be on the stigmatization surrounding depression. Depression is also of particular interest because it is a common comorbidity with other diseases such as cancer, heart disease, and HIV [23]. For PLHIV and at risk individuals, the estimated lifetime prevalence of depressive disorders ranges from approximately 20 to 60% [22]. For this reason, the World Health Organization (WHO) recommends task sharing between mental and physical health practitioners to improve comprehensive health outcomes.

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HIV/AIDS has been historically associated with considerable psychiatric morbidity and societal stigmatization. The frequency of depression for PLHIV was twice that of individuals who do not have HIV [22]. When shaming and criminalization proved unsuccessful in slowing the spread of the disease, the international community mobilized targeted programming through organizations such as UNAIDS (the Joint United Nations Programme in HIV/AIDS) to address the problem. In 2008 UNAIDS, GNP+, ICW (International Community of Women Living with HIV) and IPPF (International Planned Parenthood Federation) developed a tool to measure the HIV-related stigma and discrimination experiences of PLHIV. This tool is called the People Living with HIV Stigma Index and has been administered in more than 100 countries worldwide. After a decade of implementation, the PLHIV Stigma Index was revised to be more standardized internationally and to increase the number of qualitative survey questions. Not only was this tool specifically designed to measure stigmatization on the basis of a medical condition, but the results are intended for advocacy use [16]. For this reason, this paper will delve into the PLHIV Stigma Index with the key research question of what mental health advocacy groups can draw from this framework to guide the development of a similar tool for depression stigma. Key areas of focus will be the strengths and successes of the PLHIV Stigma Index, depression stigma, the relationship and comparison between depression and HIV, how the existing tool could inform a potential one, and finally the considerations and drawbacks of this plan. The concluding discussion will consider existing destigmatization campaigns and policy, call for future research, and present some tentative recommendations.

Research Methodology

This project was conducted using mixed methods. For understanding depression stigma, this process included a thorough review of existing literature that was then augmented by an

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interview with a psychiatrist. In order to learn more about the PLHIV Stigma Index, the majority of digital information was identified on the PLHIV Stigma Index website, run by the parent organization GNP+. Finally, two experts on HIV, specialized the global public health arena and with the PLHIV Stigma Index, were interviewed (see appendix for interview questions).

The existing research on depression stigma was sourced from academic databases such as PubMed, Google Scholar, and the Claremont Colleges Library. These studies were conducted in various countries and cover a broad range of demographics and specified topics. This variety allowed established comprehensive understanding of what the scientific community is currently doing to clarify the concept of depression stigma, know what causes it and what can successfully combat it.

On the PLHIV Stigma Index website, there are a variety of resources intended to help support networks with research administration, implementation, and application to advocacy campaigns. Furthermore, they have country reports from approximately 90 global locations. These country reports are drafted by the support organizations that conduct the surveys in each country, meaning that each report has a specialized layout, objective, and language that best fits their needs and priorities. This is important to note because it makes it difficult to compare the results, which is why in 2018 a standardized approach was implemented.

The first interview of this project was conducted with Swiss-based psychiatrist, Dr. Eytan. In this group interview, the interviewee spoke on self-stigma, cultural norms, differences between general healthcare settings and mental healthcare settings, among other things. The second interview conducted was with Pim Looze, the program officer of the PLHIV Stigma Index at GNP+. She spoke about her role with regards to the Stigma Index, an

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overview of the tool and its objectives, and theorized on this research question of how the PLHIV Stigma Index could inform a similar tool for mental health stigma. The final interview of this research project was with the senior advisor of human rights and law at UNAIDS, Dr. Emily Christie. In this interview, Dr. Christie spoke on the role that UNAIDS has in the PLHIV Stigma Index, HIV stigma, how criminalization interacts with healthcare, and contributed her thoughts on the use of a similar index for mental health.

The mixed methods approach was adopted because the nature of this project is speculative, so it was necessary to understand the existing literature alongside expert opinion. For the interviews, the initial verbal and ongoing written consent was and is continually being obtained by the interviewees. Interview subjects were identified through their connection with the School for International Training as lecturers or through their role at relevant organizations and they were contacted via email. At any point if the participants wish to remain anonymous or withdraw their opinion, they are able to do so.

The majority of the limitations of this study relate to the interview process. Of the four organizations involved in the development of the PLHIV Stigma Index, I was only able to meet with representatives from two. Furthermore, the representative I met with from UNAIDS was not part of the PLHIV Stigma Index team. Additionally, the psychiatrist I met with did not have any particular expertise on self-stigma or mental health stigma, but rather a broader understanding of the mental health sector from a medical perspective. Another issue I ran into was the ability to access some papers for a lack of having a subscription. If I were to conduct this research again, I would have liked to get more expert opinions and dive deeper into the existing literature.

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Literature Review

There are a variety of studies on both the experienced stigma of PLD and stigma held by other members of society. Each study used a different combination of multiple stigma measurement tools such as the Attribution Questionnaire-27, the Social Distance Scale, Depression Knowledge Survey, Barriers to Care Checklist, among many others [4,7,13,15,20]. Using some of these tools, one paper found in the Journal of Mental Health utilized survey data from a university in the United States to find that feelings of alienation among PLD were significantly associated with lower perceived needs, lower help-seeking attitudes, and negative treatment expectations. Additionally, symptom severity demonstrated a positive relationship with both perceived and internalized stigma [13]. Similarly, another University-based study in the States found that among highly educated medical students there was still a widespread manifestation of stigmatization on MDD (Major Depressive Disorder), with beliefs such as depression being a disorder of weak character and antidepressants being addictive [7]. While these studies present valuable findings, it is important to note the drawback of surveying university populations. While young adults and university students are an at risk group for mental illness, these surveys fall short in capturing the experiences of PLD in the broader community and outside of an educational environment [3].

The most commonly used validated framework that I came across in my research was the Depression Stigma Scale (DSS). The DSS is made up of two subscales, one of personal stigma and one of perceived stigma. The personal stigma scale is made up of 8 statements and the perceived stigma scale contains 9 statements, each of which subjects would rate themselves on a five-point scale from strongly disagree to strongly agree. Designed in Australia, this scale is a widely used psychometric tool with demonstrated validity [11]. While having proven

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helpful in broadening the scientific community's understanding of depression stigma, the DSS is the foundational step in the development of a more comprehensive tool. This is where mental health professionals and activists can utilize the PLHIV Stigma Index build a community-based, standardized approach.

In Portugal, one group explored the psychometric properties of the DSS as it relates to gender. They found that Portuguese women presented lower scores of personal stigma and higher scores of perceived stigma than Portuguese men [4]. Inversely, a Canadian study also using the DSS had a higher proportion of surveyed males endorsing stigmatizing attitudes of male depression. This same study also revealed that stigma of male depression and anxiety was most frequently coming from people with direct experiences of depression or suicidal ideation [18]. In an analysis of an anonymous Chinese social-media site, using the DSS with the exception of workplace and voting based discrimination, another study found 6% of observed posts exhibiting depression stigma. This group found that the most popularly endorsed idea was unpredictability stigma (the idea that PLD are unpredictable), with female users more likely to disseminate this type of stigma while male users were more likely to endorse the idea that depression is glorified [15].

Just as gender-based differences have been of particular interest to stigma researchers, ethnic and cultural differences have also been thoroughly explored. In a phone survey of German citizens, another group of researchers found that when presented with the same vignette of a PLD with one key difference of the immigration and socio-economic status of the subject, respondents felt more sympathy for the person when they were thought to be a Turkish immigrant. This study showed the rationalization of depression can make it seem more valid in the public eye despite presentation of the exact same symptoms [14]. In another Canadian

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study, researchers compared the stigma between individuals of Asian and European descent. They found that Asians stigmatize individuals with depression more than Europeans. This was attributed to the perception of social norms, a social dominance orientation and conservative values in Canadian Asian communities [20]. This issue of intersectionality was explored in relation to an idea called the Stigma Complex. With the complicated nature of interacting stigmas based on multiple group identities, the Stigma Complex is a systematic approach toward understanding the interrelated systems structures that divide groups. In my meeting with Dr. Christie, she mentioned how a person with HIV could still hold prejudice for another PLHIV based on their involvement in sex work, use of drugs, sexuality, etc. [2]. We see this at play with mental health stigma between different groups in the aforementioned studies. Another potential area of future research could be the stigmatization between different groups of people living with different mental illnesses or neurological disorders. For example, what would be the attitudes between two groups of PLD, one with people who also suffer from substance use disorder (SUD), and another group who does not

Analysis

Strengths and Successes of the Existing Model

The PLHIV Stigma Index has been a catalyst for change in over 100 countries around the globe. The data collected in each administration of the index has been used to make evidence-based recommendations and targeted advocacy interventions for PLHIV. One example of how the reports have guided change for the lives of PLHIV is when the Uganda

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Network of Young People Living with HIV/AIDS (UNYPA) organized a beauty pageant for young PLHIV to challenge stigma head on [8]. Another example of putting PLHIV Stigma Index results into action is how the Zimbabwe National Network of People Living with HIV (ZNNP+) partnered with the South Africa AIDS Dissemination Service (SAfAIDS) to design activities based on survey results that revealed stigma and discrimination in religious settings. Together ZNNP+ and SAfAIDS focused on cultivating stronger relationships with religious leaders and developed a framework for faith communities to reduce stigma [9].

While these are just two examples of ways that results have manifested in social action, advocacy is the final stage of the six stages of implementation for the PLHIV Stigma Index. The first step is preparation. This is where local organizations complete the logistical steps that lay a foundation for the research to occur. The organizations then enter a planning stage for sampling and budgeting. This is also where they apply for ethical and technical approval from national review boards. Next the country teams prepare for data collection with field testing, system set up and personnel training. Stage four is when the actual questionnaire is administered. The teams then analyze their findings and develop a report. In the advocacy phase the organizations then disseminate this information to relevant stakeholders, the PLHIV Stigma Index team at GNP+ and implement advocacy plans based on the garnered evidence [9]. Developed by international experts and grassroots organizations, this specific process of implementation is almost as important as the results themselves [16].

When breaking the process down, it becomes clear that the bulk of the work is done within local networks, and this is by design. When I spoke with Pim, she told me about how the

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PLHIV Stigma Index team at GNP+ mostly works to coordinate international management and provides technical support for country teams when necessary [16]. This is because when the index was first developed researchers recognized the importance of community networks and decided to build a peer-to-peer model. With criminalization of sex work, drug use, and the LGBTQ+ community it is also important to tap into local organizations that have more information on and ability to get into contact with key populations. The PLHIV Stigma Index is made by and for PLHIV which is something that everyone involved takes very seriously. One piece of anecdotal evidence on this from Dr. Christie pertains to a time when she had to “beg and plead” for a copy of the survey as part of a project she was working on at UNAIDS because she is not a person living with HIV [2]. There are many reasons for this peer-to-peer administration model. For one, it is empowering for PLHIV to be directly involved in changemaking within the public health arena because it provides with them agency and power over the problems their community of PLHIV have experienced. When the PLHIV Stigma Index was implemented in New Zealand to learn more about the experiences of Māori population living with HIV, one participant reported that they “are now in a better position to call out HIV stigma and discrimination when I see it” further reinforcing this concept of educational empowerment. Another reason why the peer-to-peer model is effective is because of the emphasis on qualitative data analysis in the Stigma Index 2.0. Qualitative data allows people to express themselves in their own words and when their interviewer is also a PLHIV there is an increased ability to establish a bond. This also increases the likelihood that participants will feel comfortable sharing the more personal aspects of their story because of the sense of trust and understanding. The final reason why this peer-to-peer approach was implemented is because of the GIPA, the Greater Involvement of People Living with

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HIV/AIDS, principle that was established in 2007 by UNAIDS [9].

Along with the community involvement, peer-to-peer format and focus on advocacy, there are a few more aspects of the PLHIV Stigma Index that set it apart from other data collection methods. The first being their emphasis on the capacity building of local organizations by facilitating growth and collaboration with other networks of PLHIV in the surrounding areas. The central PLHIV Stigma Index team acts as a support system and provides all the necessary documents and guides to ensure that the research runs as smoothly as possible. Another aspect of this data collection model is the sampling tactics. There are four key populations of PLHIV and those are men who have sex with other men, transgender people, sex workers and people who use drugs. When teams sample for research participants the goal is to get an even distribution of these key populations [16]. This differs from traditional sampling that aims to reflect the general population of an area. The reason that most researchers strive for a sample population as similar as possible to the general population is because the results can more easily be applied beyond the sample population. For the purposes of this study, it is more important to sample the groups most at risk of stigma and discrimination because the results are intended for targeted advocacy use not for the expansion of scientific literature on the broader populations of PLHIV. Furthermore, the survey is incredibly thorough. Spanning about 90 minutes per interview the survey has about 80 questions covering categories of internalized stigma and resilience, demographics, external stigma and discrimination, education related stigma, women's rights, etc. [16]. Through this, researchers also have the ability to learn about gaps in knowledge within the HIV community. For example, when administered in Botswana the Stigma Index found that 90% of respondents had not heard of the UN Declaration of commitment on HIV/AIDS or the National Strategic

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Framework on HIV/AIDS [1]. With this the organizations in Botswana were able to fill these gaps and educate PLHIV on their rights. Even if there are not necessarily gaps in knowledge, the PLHIV Stigma Index also has the ability to assess help seeking behaviors, like in Louisiana when most participants were aware of support organizations that work to fight stigma but a small portion of those PLHIV were actually involved with those organizations. In this same study, which was the first full-scale implementation of the PLHIV Stigma Index in the United States, researchers were also able to collect data on layered stigma, a very nuanced and important aspect of discrimination that many scientific communities have attempted to measure [12].

Depression Stigma

The stigmatization of all types of mental illness has been a pervasive issue throughout history and across the globe. To this day stigma continues to constrain people living with depression through widespread institutional failures and social ostracization [4]. A large majority of the stigmatization that people experience comes from their own families. In certain circles, depression is seen as shameful, and people believe that it reflects negatively on the families of PLD [20]. PLD have also reported instances of family members minimizing the experience of depression, equating it to normal sadness or a phase of distress that will eventually pass [17]. While familial stigma is a difficult to process problem in and of itself, this points to the larger aspect of depression stigma that is the lack of understanding what MDD is and where it comes from. In a survey of Arab adolescents who experience and do not experience depression, most adolescents believed that stressful life events, social factors and one's weak will are the primary causes of depression. In fact, these findings also suggest that

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those who attribute the causes of depression to the biological etiology more than the environmental etiology were less likely to hold stigmatizing views of PLD [5]. This supports the idea that stigma comes from misinformation, but there are also other sources to consider.

In my interview with Dr. Eytan, he discussed how stigma can also come from perceived differences, drawing on his knowledge of cultural barriers in psychiatry. These perceived differences lead to an inability or unwillingness to empathize with PLD. This is what contributes to the stigmas surrounding PLD being unpredictable, unreliable, delusional, lazy, or having weak character [6]. This is also supported by the fact that people estimate that the odds of themselves getting or experiencing depression for a prolonged period of time to be very low (1% or fewer) [7]. When considering the cultural and social differences between the types of stigma that different groups experience it is also important to consider the effects that a person's outward identity may also impact the stigma they experience. This could also impact the stigma that they would inflict upon themselves and others. Dr. Christie mentioned that within the PLHIV community, there are still elements of stigmatization towards sex workers or those in the LGBTQ+ community. As previously mentioned, this could potentially translate to mental health as people who experience other stigma having worsened experiences with depression stigma. There could also be stigmatization between people who are diagnosed with other mental illnesses against those with depression [2]. Furthermore, PLD could discriminate against other PLD who experience different symptoms or have differing treatment plans.

Regardless of the origins, stigmatization leads to gaps in service and decreased helpseeking behaviors [23]. This only serves to perpetuate the stigma of depression because people further internalize social stigma and allow their own conditions to worsen [7]. Many PLD get to a point where they have decreased perceptions of their own needs [13]. If patients

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aren't able to accurately assess their own symptoms, then they are not going to be able to effectively communicate with healthcare professionals even if they do decide to seek treatment.

Similarities and Differences between HIV and Depression from a Societal Perspective

When I spoke with Dr. Eytan, he mentioned that in both the cases of HIV and depression, the source of stigma is a moral judgement. With HIV having moral attitudes surrounding sex, sexuality, and drug use while depression conflicts with moral codes that denounce inaction and emotional expression [6]. In both instances these stigmas have manifested in healthcare discrimination. When asked about their experiences with stigma and depression one respondent commented on how often “insensitive doctors” have given them the “no pain no gain speech.” This ties into a broader theme of PLD most commonly reporting issues with healthcare services and community response [17]. When it comes to HIV, Dr. Christie touched on the paternalistic and stigmatizing approach from doctors, following a “doctor knows best” attitude that leads to individuals being denied care and services despite their wishes [2]. This discrimination and disregarding of needs leads to fear around healthcare settings and hesitation to seek treatment. It has also been noted how people with mental illness will be delegitimized and turned away from general healthcare facilities due to stigmas that they will disturb other patients [6]. Both of these populations also fear the labels of depression and HIV due to the societal negative connotations. Nearly $\frac{3}{4}$ of respondents a PLHIV Stigma Index reported that they were fearful to tell people about their HIV status [21].

Additionally, depression and HIV are common comorbidities. In a cross-sectional study examining stigma, discrimination, and depression among PLHIV, depression scores were significantly and positively correlated with self-stigma and inversely correlated with social

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support networks [22]. It was also found that women living with HIV have higher rates of depression than men living with HIV and women who are not living with HIV. This connects to the idea that factors such as gender can affect a person's interaction with the healthcare system and why intersectionality is an important element of this discussion. In fact, depression and HIV present together so frequently that the WHO recommends task sharing between mental health efforts and HIV specific efforts. This is because treating depression could also assist in adherence to care and clinical outcomes for PLHIV [23]. When the PLHIV Stigma Index was administered in New Zealand, they found that a third of participants reported feelings of shame and worthlessness associated with their HIV diagnosis and 54% of those interviewed did not receive counseling for any mental health ailments they experienced. Furthermore, Māori PLHIV were found to be three times as likely to be struggling with their mental health than the general New Zealand population [21].

One difference between the way that these two diseases are externally viewed connects with the fact that HIV is a communicable disease and depression is a non-communicable disease. Dr. Eytan expressed concerns regarding this research concept because from his perspective a considerable amount of the discrimination experienced by PLHIV stems from the ways that HIV can be transmitted [6]. When I spoke with HIV/AIDS experts Pim Looze and Emily Christie they did not foresee any significant problems in applying the PLHIV Stigma Index model to mental illness stigmas [2, 16]. This is because while the prejudices have roots in different pieces of misinformation, stigma is the same mechanism in both instances. Furthermore, the proposed mental health tool would need to be developed independently of the PLHIV Stigma Index, mostly drawing inspiration from the methods of the existing model due to its successful and unique approaches.

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The more relevant distinction between the types of stigma experienced by PLHIV and PLD is the fact that all the lifestyles of all of the four key populations of PLHIV – men who have sex with other men, sex workers, transgender individuals, and people who use drugs – are criminalized in many parts of the world [2]. While PLD might experience other types of systemic discrimination, such as school absence policies or workplace time off protocols, they would not find themselves at risk of imprisonment or execution because of their medical diagnosis or lifestyle. There is a common population of interest between depression and HIV, that being people who use drugs, so it is possible that this population would experience the barriers to healthcare that stem from drug criminalization. This difference does not mean that mental health stigma is of a lower priority than HIV stigma, it simply means that the advocacy and policy tactics to debunk these stigmas would differ. This once again supports the need for a tool similar to the PLHIV Stigma Index because it shows the necessity to understand the intricacies of depression stigma to inform more accurate and targeted social change.

The Need for a Stigma-oriented Analytical Tool in Mental Health

As noted in the literature review, the majority of the existing research surrounding depression stigma focuses on populations who do not have depression with the goal of understanding the external/societal views of people with depression. This is a flawed model for multiple reasons. For one, the majority of these studies sample niche populations such as university students or users of certain online platforms [3,7,13,15]. While these studies are beneficial for understanding why certain groups would hold stigma against PLD, they do not identify the tangible negative effects of these stigmas. PLD are a primary source of not only what types of social stigmatization a person can experience, but also the ways that this

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manifests in self-stigma and negative healthcare outcomes. Another reason that the existing literature does not capture the full picture of stigma is the fact that the majority of these studies are built around hypothetical scenarios which are utilized to gauge participant reactions. The best way to understand the stigmas that exist in society is to speak with the groups of people that experience those very stigmas. In the Medical Journal of Australia, a qualitative analysis was done on interviews with PLD. Identifying focus group participants via engagement with *beyondblue*, a nationwide depression education and advocacy campaign, this was one of the few studies I found in my search that worked directly and exclusively with PLD to understand depression stigma. This study was able to gather compelling quotes, such as “how often do you see flowers and chocolates brought into a psychiatric ward?” and “I feel like my basic humanity has been denied,” that speak to the perspectives of a PLD who experience stigmatizations [17]. These anecdotes of first-hand experience with depression stigma are valuable for people who do not experience depression and mental health activists alike to establish a sense of empathy between the two groups. Furthermore, we can deepen our understanding of how these stigmas act as a barrier to treatment and policy change.

Healthcare budgeting is one of the biggest systemic barriers stalling the development of a flourishing mental health sector and improved mental health outcomes. General healthcare budgets tend to allocate funds based on categories such as hospital or primary healthcare facilities, rather than by health conditions. This means that funding is decided on a facility level [23]. Stigmatization directly impacts this because it delegitimizes the experiences of certain patients and puts their conditions on a lower priority than other diseases. This has negatively impacted those with mental illness due to the invisible and deeply personal nature of the conditions. This is a vicious cycle when self-stigma is considered because even if there are

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budget increases, higher levels of self-stigma have been associated with a decreased likelihood of seeking treatment [7,13]. This is one of the many failures of the global health community in facilitating the mental and physical wellbeing of all people. PLHIV in Louisiana also expressed that paradoxically the most support and the most stigmatization come from healthcare workers [12]. Considering the fact that stigmatization can be directly connected with worsening health outcomes, it becomes clear why there is a constant need to emphasize anti-stigma interventions in healthcare [7].

In my interview with the PLHIV Stigma Index representative at GNP+, she mentioned how “most stigma come from misconceptions,” and this is the most important concept with regards to understanding how to eliminate the stigmatization of any group of people [16]. If we have a clear understanding of what types of stigma people experience, what misconceptions are driving this stigmatization, how these societal attitudes manifest internally and what effects that can have on health-seeking behaviors, we have all the required datapoints to shift the political and social climates. This is why it is absolutely necessary to not only call for mental health advocacy and destigmatization campaigns, but to tailor those programs to their target audiences for maximum effectiveness [11,16]. Targeted public destigmatization campaigns start with good evidence and a clear understanding of the problem [8]. It is for this reason why a standardized mental health stigma tool, much like the PLHIV Stigma Index, is needed to better the future of healthcare stigma data collection and advocacy.

How the PLHIV Stigma Index Could Inform Depression Stigma Measurement

Now that the strengths of the PLHIV Stigma Index and the necessity for a stigma data collection methodology have been established, it is time to combine the two ideas. While stigma data analysis has been conducted in the mental health sector, there is an overwhelming

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amount of scales and methods. All of these concepts would see benefits if they were streamlined into a standardized and sophisticated model like the PLHIV Stigma Index. This hypothetical tool could draw inspiration from the peer engagement, partnership with existing networks, mixed methods, and advocacy-oriented approach.

For starters, there are four key populations that have been identified for PLHIV and the Stigma Index focuses its efforts on these groups. For depression, the rates are highest in adolescents ages 14 and over, low income households, university students/young adults, and those living with an existing chronic health problem, learning disability or psychiatric diagnosis [3,5]. Further research would be necessary but it would be beneficial to also structure a mental health stigma analysis tool around key groups.

According to the WHO, community-based mental health care is more accessible, acceptable and produces better outcomes than institutional care [23]. For this reason, the mental health sector could also focus on capacity building like the PLHIV Stigma Index. This would facilitate a comprehensive approach towards improving depression outcomes because in the data collection process, increased support and funding would increase local networks ability to help a greater population.

In terms of magnifying impact, the use of a standardized approach within various populations would be in favor of mental health advocacy across the board [16]. Each of the studies I have used in this paper today come from a variety of locations across the globe, covering multiple cultural groups. If this research was centralized and used the same framework it would be far easier to compare the findings. This is why the PLHIV Stigma Index also exemplifies the benefits of international data collection with core organizations to act as support for individual data collection teams. Furthermore, with HIV related stigma also acting

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as a barrier to depression support networks for PLHIV and PLD, the comorbidity of these two illnesses is not something to ignore. It was found that perceived social support mitigates the effects of HIV related depression [22]. If the process and standards of a depression measurement tool were similar enough to that of the PLHIV Stigma Index, this opens up an avenue for research on the interactions of these illnesses and their stigmas.

The PLHIV Stigma Index has shown that effective advocacy is evidence-based [8]. The questions of current stigma measurement tools for depression are designed for scientific analysis in terms of reliability and validity. Their primary goal is understanding and knowledge, and while this holds its own value, the PLHIV Stigma Index questions are designed to be easily translated into advocacy [16]. With direct aims at influencing the opinions of people in power to shift policy and systems functioning the PLHIV Stigma Index is a tool for change [8]. Not only does the PLHIV Stigma Index provide local organizations with the ability to collect evidence, but GNP+ also provides comprehensive guides on how to translate the findings into briefing papers, testimonies, media content, op-ed articles and social media campaigns [10].

Beyond the advocacy applications, the peer-to-peer format is something that has not been tried in the realm of mental health. Considering the grave need for improvements in funding and resource allocation to mental health and NCDs in general, acquiring firsthand experiences as evidence has been extremely effective in the case of the PLHIV Stigma Index. People who have experienced stigma, especially self-stigma, are less likely to be willing to share those feelings with a stranger [2,16]. If that stranger also experiences depression, then there would be a greater ability for the two to connect and it is likely that this would promote better, more accurate results.

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Finally the general categories of questions in the PLHIV Stigma Index could serve as a valuable guide. All of the categories— internalized stigma and resilience, demographics, external stigma and discrimination, education related stigma— are also applicable to PLD [16]. Another study that worked directly with PLD found 15 key themes of stigma experience by PLD, primarily related to healthcare and community interactions [17]. These findings could help guide the development of depression specific questions that fall into the same categories as the PLHIV Stigma Index.

Key Considerations and Potential Drawbacks

One of the main concerns that was expressed in my interviews was the feasibility of translating the peer-to-peer format for PLD [2,6]. I was not able to find any evidence in favor or against this concern as such studies have not been conducted yet. Although this concern seems to be in line with some of the existing depression stigma on the laziness or unreliability of PLD, it is worth researching. PLD exist in many facets of society and if it is plausible that they would be able to sit down for a 90-minute interview or focus group, it seems feasible that they would be able to conduct that interview and be involved in the data collection process. The primary concern with regards to this is the ethical considerations of working with adolescents and vulnerable populations. Continued and informed consent, human subject reviews, ethical review boards and support institutions would all be necessary elements of the proceedings of this research.

Although PLD and those living with anxiety are the most common, it has been shown that these groups are less stigmatized than those with schizophrenia and alcohol use disorder [14]. The demand for such a tool in mental health is called for, but the focus on depression

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specifically is debatable when compared with others in the mental health community. This ties into the potential in-group stigmatization mentioned earlier.

Furthermore, it would be hard to find the distinction between layered elements of stigma. As much of the existing literature has found, stigma varies between groups. For example, ethnic minorities and people with low socioeconomic status (SES) who also have mental illness most often experience double stigma [14]. It has also been found that men with mental illness are also more likely than women to have stigmatizing views towards other men with mental illness [18]. Additionally, inverse causality could potentially be at play as marginalized groups are at greater risk for depression among other mental health issues [23]. It could prove difficult to disentangle the effects of different stigmas and identities.

Another important consideration in this suggestion is considering the identification of research participants and local organizations. The PLHIV Stigma Index was designed as an effect of the high volume of community engagement being conducted by UNAIDS [2]. There is no such existing international framework that exists for mental health so it could prove far more difficult to establish those relationships. There are also potential barriers in identifying those with depression because there are such low levels of treatment. One way to combat this would be to have participants self-report their experiences with depression but this would weaken the validity of the results. Similarly, with self-stigma at play it is possible that we miss key groups who discount their own experiences to such a degree that they would not participate in the survey. The best way to account for these gaps in data is to readminister the survey in the same places on regular interviews in hopes that advocacy campaigns are successful and increase the ability to capture the experiences of previously neglected populations. This is also not an issue that the PLHIV Stigma Index was able to avoid either. Dr. Christie shared that in a

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recent report, UNAIDS estimated that 50 million members of key populations of PLHIV are missing from the current numbers due to unsafe political climates and criminalization [2].

Finally, the issue of funding and capacity is a reason why this research is necessary but it is also a plausible reason as to why it may not be possible right now. Mental health networks are severely underfunded and under supported by health ministries globally, not to mention the price gouging in the private mental health sector [23]. If these groups are unable to provide adequate care for those in need, they most definitely do not have the capacity to conduct comprehensive, ongoing research.

Conclusion

The AIDS epidemic, beginning in the early 1980s continues to be a global public health issue to this day. Taking over 40 million lives in its wake, the global health community has taken measurable actions to increase support and awareness for this disease. Among many things, the PLHIV Stigma Index was developed and has been a key tool for change in the last two decades. With record-breaking rates of mental illness during the isolation of the Covid-19 pandemic, now it is more important than ever to once again mobilize the global health community into systems change for the betterment of mental health programs. This is a call to action for the development of new programs and initiatives to legitimize and treat the mental challenges that millions of people experience around the world.

The main takeaways from this paper are the stigma surrounding depression, the effects of those stigmas on PLD and the mental health sector, the PLHIV Stigma Index, and how the mental health community can learn from the successes of that model. This was achieved in discussing the budgeting issues from international to local levels, mental healthcare outcomes

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and patient behaviors, analyzing current depression stigma measurement techniques, and exploring the intricacies of the PLHIV Stigma Index.

Needless to say, going forward with a plan like this requires copious amounts of research and preparation. Some important questions that require answering concern what organizations would be involved, where would a pilot program begin, who (if anyone) would be the central governing body, and what is necessary to fund and maintain an ongoing data collection program of this caliber. Fortunately, the PLHIV Stigma Index has paved the way and now the bulk of the research would involve what is needed to transfer the model to the mental health sector. Furthermore, this idea cannot stop there, but further exploration into other aspects of healthcare stigma and discrimination would be crucial for reforming the current systems.

Drawing from other destigmatization campaigns, there are some valuable recommendations for efforts to make in the meantime of developing this standardized data collection tool. Video campaigns have shown to reduce depression stigma and improve helpseeking attitudes [3]. In Australia there was a successful media campaign called *beyondblue* that focused on increasing community awareness and influencing policy on healthcare services [17]. Furthermore, in New Zealand the PLHIV Stigma Index results even found evidence in favor of publicly accessible counseling and support referral programs to address the mental illnesses that stem from HIV-related stigma.

The ultimate goal is to achieve people-centered, recovery-oriented human rights based care for all people living with physical and/or mental health conditions [23]. This can be achieved through many avenues, but the most effective way to achieve this starts with a large base of knowledge on and evidence of the problems that exist.

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Appendix

Abbreviation List

AIDS – acquired immunodeficiency syndrome

CD – communicable disease

CMC – Claremont McKenna College

DSS – depression stigma scale

GNP+ – Global Network of People Living with HIV

HIV – human immunodeficiency virus

ICW – International Community of Women Living with HIV

IPPF – International Planned Parenthood Federation

LGBTQ+ – lesbian, gay, bisexual, transgender, queer and/or questioning individuals

MDD – major depressive disorder

NCD – non-communicable disease

PLD – people living with depression

PLHIV – people living with HIV

SAfAIDS – South Africa AIDS Dissemination Service

SES – socioeconomic status

SIT – School for International Training

SUD – substance use disorder

UNAIDS – Joint United Nations Programme on HIV/AIDS

UNYPA – Uganda Network of Young People Living with HIV/AIDS

WHO – World Health Organization

YLD – years lived with disability

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ZNNP+ – Zimbabwe National Network of People Living with HIV

Interview Questions

Dr. Ariel Eytan:

What is your understanding of and professional experience with patients who have selfstigmas regarding their mental illnesses?

You have researched the impacts of cultural identity and migration on mental health status, would you be able to speak on how the cultural differences between patient and practitioner could tie into the stigmatization of certain illnesses?

In your experience as a medical professional, how do you think that psychiatrists can abandon their stigmas to adequately provide care to there patients?

What are the pitfalls of stigmatization in psychiatry and how do you think that they could be improved?

What similarities do you think exist between the stigmatization that PLHIV experience and people living with mental illness?

There is a common population of interest between those living with HIV and those living with depression and that is people who use drugs, what, if any, is the relevance of this to the topic at hand?

Pim Looze:

Would you be able to provide a brief overview of what the PLHIV Stigma Index is, what role GNP+ plays in the implementation of this index, and your position on the PLHIV Stigma Index team?

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Considering that the tool calls for direct engagement with vulnerable populations, how do you go about respecting the ethical considerations in these studies?

What was the reassessment process for the Stigma Index 2.0 in 2018?

What are some of the key areas of focus within the questionnaire?

How do you deal with the gaps in data that result from people refusing to get tested for HIV?

Seeing as HIV is a communicable disease, while depression is a non-communicable disease, what proportion of the survey deals with the stigmatization that comes from misinformation on or prejudice towards how HIV is transmitted? How, if in any way at all, would this translate to a tool for mental illness?

What aspects of the PLHIV Stigma Index do you think would be applicable to a stigmatization questionnaire for depression?

What other recommendations or reservations do you have regarding this research concept?

How long does the PLHIV Stigma Index take to administer?

Dr. Emily Christie:

What was the development process for the PLHIV Stigma Index?

What prompted the development of the PLHIV Stigma Index?

Would you be able to elaborate on the peer-to-peer implementation model?

Do you have estimates on the gaps in data that arise from lack of testing due to fear of having HIV?

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What issues would you foresee in transferring a model designed for a communicable disease to that of a non-communicable disease? Do you think this is something that can be done?

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