Mental Illness Knowledge and Stigma of Jamaican Diaspora & First-Generation Jamaican Americans

Mental Illness Knowledge and Stigma of Jamaican Diaspora & First-Generation Jamaican Americans

A Dissertation Proposal Presented

by

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Abstract

PURPOSE: To describe U.S. Jamaican diasporan and first-generation Jamaican Americans knowledge of and stigma towards mental illness.
SPECIFIC AIMS:

1. Describe U.S. dwelling Jamaican diaspora and first-generation Jamaican Americans knowledge of mental illness and stigma towards mental illness with identification of drivers and facilitators of stigma.
2. Elicit descriptors used by Jamaican diaspora and first-generation Jamaican Americans to describe mental illness.
3. Determine association of mental illness stigma and mental illness knowledge, to age, gender, education, employment, religiosity, years living in the U.S., socioeconomic status, personal history of mental illness, and family member with mental illness.

FRAMEWORK: The Health Stigma and Discrimination Framework.
DESIGN: Cross-sectional descriptive survey.
RESULTS: Jamaican diaspora years have less knowledge (mean 97.25, SD 10.27) than Jamaican Americans (mean 104.24, SD 7.74; p =.001). Participants $\geq$ 40 years had less knowledge (mean 97.05, SD 9.54) than those < 40 years (mean 102.08, SD 10.95; p =.003).
Jamaican diaspora years have more stigma (mean -.52, SD .76) than Jamaican Americans (mean -1.10, SD .73; p < .001). Participants $\geq$ 40 years had more stigma (mean -.48, SD .69) than those < 40 years (mean 1.02, SD .87; p <.001).
CONCLUSION: Older adults have less knowledge of mental illness and more stigma. Jamaican diaspora has less knowledge and more stigma than First-generation Jamaican Americans. Greater mental illness knowledge is associated with less stigma providing support for ongoing efforts to increase public knowledge of mental illness with added emphasis on word choice/terms used when talking about people with mental illness.

KEYWORDS: *Jamaican-diaspora; Jamaican-American, Mental illness Stigma, Mental Health Literacy, Drivers of Stigma, Facilitators of Stigma*

Dissertation Proposal

Introduction

There is deep mistrust of and stigma towards the mentally ill amongst Jamaicans with varied understanding as to the cause and etiology of mental illness. The varied perspectives about mental illness range from denial of its existence or treatability (Elis, 2015) to believing it may be contagious, caused by stress or thinking too much, side effects from drugs, relationship problems, job loss, spiritual and/or religious causes (including Obeah), biological problems (such as chemical imbalances), familial transmission and, "blood" (Arthur, & Whitley, 2014; Yorke et al., 2016).

Within Jamaican culture many terms are used to describe people with mental illness. These are often words that 'mark' or stigmatize the individual as an outcast or scourge to society. Words such as 'mad, sick, head nuh good,' (Arthur et al., 2010), crazy 'loco,' and 'loss him sense'(Ellis, 2015), and 'madman' (Jackson & Heatherington, 2006) are reportedly used. These are drivers and perpetuators that contribute to the negative image of mental illness, and facilitate stereotypes of the mentally ill and their families (Arthur et al., 2010).

In 2017, there were 745,000 documented Jamaicans living in United States (Zong, 2019). There is a hesitancy among some minority groups, including Jamaicans, to seek or consult doctors and/or mental health providers for mental health symptoms and a preference to seeking alternative therapies and help such as religious healing and/or mystic interpretations, including use of traditional remedies and herbs (James et al., 2014; Lacey et al., 2016; Williams, 2013). Whether or not the stigmatizing of mental health has persisted among Jamaican diaspora and first-generation Jamaican-Americans is not known. The negative impact this may have on individuals, their families, and potential reluctance to engage with the health care systems to

treat and manage mental illness is a concern. Understanding the current perspectives of Jamaican diaspora and first-generation Jamaican-Americans is important for nurses who have contact with this population in schools, religious communities, and health care settings.

Purpose: The purpose of this study, guided by the Health Stigma and Discrimination Framework (Stangl et al., 2019), is to describe U.S. Jamaican American-diaspora and first-generation Jamaican-Americans' perceptions of mental illness. A greater understanding of their perspectives and identification of some of the drivers and facilitators of stigma as it relates to mental illness will help in informing future interventions to improve acceptance of mental health diagnoses and utilization of mental health services and resources. To achieve my purpose, I will conduct the following three Specific Aims:

***Specific Aim 1*:** Describe U.S. dwelling Jamaican-diaspora and first-generation Jamaican-Americans knowledge of mental illness, stigma towards mental illness and agreement of drivers and facilitators of stigma proposed in the literature.

***Specific Aim 2**:* Elicit descriptors used by U. S. dwelling Jamaican-diaspora and first-generation Jamaican-Americans to describe mental illness.

***Specific Aim 3**:* Determine the association between mental illness stigma and mental illness knowledge, age, gender, education, employment, religiosity, years living in the U. S., socioeconomic status, and personal or family history of mental illness.

Environment and culture play a role in shaping how we think. The negative and stigmatizing way many Jamaicans view those who are mentally ill is well documented. Jamaicans ascribe many rationales to the cause of mental illness and some of these rationales exacerbate an already tenuous situation in which care is not sought because mental illness is blamed on magical/spiritual causes. Whether or not Jamaicans who migrated to the U.S. and

first-generation Jamaican Americans hold stigmatized views of mental illness will be explored in this study.

Background and Significance

Prevalence of Mental Illness

Mental Illness and its Prevalence Among Black Caribbean Diaspora and Their Children

Research conducted over three decades in Britain, shows that Blacks from the Caribbean and their children born in Britain (first and second-generation) present with psychotic disorders at a rate 5 times higher than "British White" (Tortelli et al., 2015). In the Americas, Williams and colleagues (2007), using data from the "National Survey of American Life: The Mental Health of Black Caribbean Immigrants," performed descriptive and age-adjusted analyses to examine the prevalence of psychiatric disorders among 1621 Blacks of Caribbean descent and compared their outcomes to 3,570 "African-American." Caribbean males were more likely to be diagnosed with mood disorders compared with African American males, and Caribbean females had lower odds of anxiety, substance disorders, and any psychiatric disorders than African-American females. Third-generation Black Caribbean immigrants had the highest prevalence of psychiatric disorders among all immigrant groups studied (Williams et al., 2007). Williams and colleagues (2007) report that being Black immigrant in the U.S. contributes to a higher risk for psychiatric disorders and hypothesize that this may be a reflection of increased societal stressors and decreased mobility, a status of being "Black in America" (Williams et al., 2007) .

There is a scarcity and paucity of information on the mental health of this population, and while the study by Williams and colleagues' may be old, it remains one of the most recent studies addressing this segment of the population in the U.S.

Mental Illness and its Prevalence in the United States

The diverse and myriad personalities emanating from the interactions in the human brain/mind has mystified and confounded the scientific community and the general public from the beginning of human existence. Of major interest is the question of what happens when a person has mental illness. Mental illnesses are health conditions involving changes in emotion, thinking or behavior (or a combination of these) that are associated with distress and/or problems or inability in functioning in social, work or family activities (American Psychiatric Association, 2020).

Mental illness is common. The percentage of U.S. adults with mental illness in 2019 was 20.6% (51.5 million people, 1 in 5 adults); 5.2% who experienced serious mental illness (13.1 million, 1 in 25 adults) (Substance Abuse and Mental Health Services Administration, 2020).

The Stigma of Mental Illness

In ancient Mesopotamia doctors (who were also priests) treated the mentally ill with "magico-religious" rituals because mental pathology was believed be a result of demonic possession (Foerschner, 2010). Thousands of years later, mental illness and those it afflicts are still sometimes ostracized and are treated by many societies as outcasts. Historically, limited knowledge about this malady and those it affects contributed to treating people with mental illness inhumanely.

Stigma occurs when people construct negative cognitive categories and connect these negative constructs to their stereotypical beliefs (Link & Phelan, 2001). Stigma and negative attitude towards mental illness is a worldwide phenomenon. Culture plays an important role in how a society views mental illnesses (Ellis, 2015; Mbuthia et al., 2018). Stigma leads to negative judgmental behaviors, thoughts and social labeling of those deemed to be mentally ill as

'outcasts and dangerous.' This creates many barriers in social contact, seeking and accessing healthcare, education, and job opportunities resulting in poor health outcomes for both afflicted and their families, decreased life opportunities, loss of independence and concluding in a greater burden than the mental illness itself (Corrigan, 2004; Hinshaw & Stier, 2008; Jorm, 2000; Schomerus et al., 2014).

Historical Context Related to Stigma of Mental Illness in Jamaica

To understand the historical context of stigma of mental illness in Afro- Jamaica's population, a brief understanding of their genesis from slavery is warranted. Slaves from West Africa brought to Jamaica came with religious beliefs that amalgamated with those of the colonial powers resulting in a hybrid belief system that continues to present day. The history of Jamaicans beyond the slogan "no problem, man" is complex and at times, bitter. During the British reign, African slaves were brought in as plantation workers to fill the void left by Arawak Indians who had succumbed to various foreign diseases under the previous colonizers, the Spaniards. These slaves were viewed as "tools of production," "void of human feelings, emotions and mental needs" ((Pitman, 1926). Slaves deemed violent, as well as those thought to be "disturbed mentally ill" or "mad," were "*involuntary committed"* or incarcerated instead of receiving medical care (Hickling & Gibson, 2012; Pitman, 1926), and those exhibiting signs and symptoms of mental illness were considered "possessed" by evil spirits (Hickling, 2019; Morrison et al., 2015).

Mental Illness in Jamaica Post-Colonization

In August of 1962, Jamaica gained semi-independence from Britain which allowed for a new approach caring for the mentally ill. Efforts for the deinstitutionalization of the mentally ill resulted in passage of legislation in 1974 to address mental health in the country, and in

particular, those held in asylums (Hickling, 2019). This deinstitutionalization effort, coupled with community engagement, public education on mental illness and "psychohistoriography" (*amalgamation of dialectics and psychotherapy which examine psychological implications over timeline of historical anecdotes and phenomena*) led to improved treatment, and reduction in institutionalization and stigma towards mental illness (Hickling & Gibson, 2012).

The generation which witnessed these changes hold less stigma against the mentally ill than generations after and/or before them ((Hickling et al., 2011; Youssef, 2018). Despite deinstitutionalization efforts over the last 40 years, there are mixed views amongst Jamaicans on the success, effectiveness and the societal impact of the program. Some do not believe that community integration of the mentally ill is in the best interest of patients, families, or society. A qualitative descriptive study using a convenience sample (n=22) of psychiatric workers (17 females and 5 males) addressing deinstitutionalization, found a majority (n = 13) believed institutionalization of patients with mental illness was in the patients best interest, due to fear that patients would deteriorate if they were reintegrated in the communities (Pusey-Murray et al., 2014). These views highlight the persistent negative perception and stigma with associated discrimination towards the mentally ill in Jamaica and, likely contributes to the failure of the efforts made by the Ministry of Health in scaling up a deinstitutionalization program nationally across the Island (Pusey-Murray et al., 2014).

Lack of deeper insight on the genesis of mental illness and its manifestation among some Jamaican causes some to attribute causality to Obeah. Obeah practice, a criminal offence in Jamaica (but with many adherents), is like "Myalism," which is a folk religion whose adherents believe it has powers to communicate with ancestors. It typically involves ritualistic drumming,

dancing, spirit possessed excisions, sacrifice, and herbalism *((The Obeah Act 1898; Wedenoja &* Anderson*, 2013).*

The British anthropologist Madeline Kerr studied Jamaicans from 1947-1949, pre-independence, and wrote that there were many drivers contributing to personality disorders in Jamaicans. Kerr alluded to loss of identity resulting from slavery, conflict of religious versus mystical/magical beliefs, racial divide among Jamaicans due to skin hue/color and colonization which propagate continued psychological bondage (Kerr, 1963a).

Perception of Mental Illness

Perception of Mental Illness in the Caribbean

Decades after Kerr's initial work on factors contributing to Jamaican personality disorders and stigma among Jamaicans towards mental illness, researchers are still trying to understand the drivers, facilitators and stigmatizing views of mental illness in Jamaica. Arthur and colleagues (2010) conducted an ethnographic qualitative research study amongst 127 community members in Jamaica. Participants understanding of stigma was in line with findings in western countries with many participants describing it as a "negative assumption," "like bigotry," "a learnt behavior," or referred to it as "a strain" (Arthur et al., 2010). Participants rated their emotional response towards those with mental illness as "fear and [perceived] dangerousness," with avoidance being the most common behavioral response. The term "madness" was used to reflect those who portray violent behavior and/or are homeless (Arthur et al., 2010).

Jackson and Heatherington (2006) surveyed 1218 young Jamaicans' on the island to gain understanding of their attitudes toward mental illness and willingness to interact with those assumed to be mentally ill. Overall, participants preferred greater distance between themselves

and someone with a history of mental illness (Jackson & Heatherington, 2006). Consistent with other research on Jamaicans, these participants viewed mental illness as a defect due to personal and/or family weakness and as illustrated by the terms used "madness and madman," view mental illness in a stigmatizing manner (Jackson & Heatherington, 2006). Participants, especially those of higher economic status, endorsed the overall belief that mental illness was a result of "failure of will or benevolence" (Jackson & Heatherington, 2006).

Medical and nursing students in Jamaica also hold negative views towards the mentally ill. Youssef (2018) compared the knowledge and attitudes of 114 medical students from five anglophone Caribbean islands including Jamaica, attending medical school in Trinidad from pre- to post-clinical experiences. Fifty percent believed those with schizophrenia had "multiple personality" (Youssef, 2018). Another significant finding was that 36% post-clinical medical students did not know that "mental illness is a global health problem." Knowledge and attitudes toward mental illness did show significant improvement from year-one to year-five: but stigmatization towards mental illness persisted despite increase in knowledge about the disease (Youssef, 2018).

In another study looking at attitude towards the mental illness in Jamaica (Bennett & Stennett, 2015), 143 third-year nursing students enrolled in a psychiatric and mental health nursing course were recruited to examine their "Attitude Towards Mental Illness." These student nurses (n=102) had fear and an overall negative attitude towards those with mental illness, perceived them as dangerous, and cold-hearted. These findings are consistent with the findings by Jackson and Heatherington (2006), that young Jamaicans have a negative impression of the mentally ill.

Knowledge, view, outlook and attitudes towards mental illness among college students in the Caribbean (Youssef et al., 2014) was measured by a cross-sectional survey with a convenience sample of 673 college students in the Caribbean using the Knowledge About Mental Illness scale (Wahl et al., 2012) and the "Attitudes to Mental Illness Questionnaire (AMIQ) (Luty et al., 2006). Results were consistent with high stigmatization toward those with mental illness and, less empathy towards those with schizophrenia because of the idea that individuals with schizophrenia had multiple personalities and were violent (Youssef et al., 2014). Those who knew someone with mental illness (n= 282) scored higher on knowledge questions than those who did not know someone (58.9±5.6 vs 57.6±5.9, p=.006). Females also scored higher than males (58.7±5.4 vs 57.4±6.2, p=.005).

Misconception of those with mental illness is reported by Arthur and Whitley (2014) who conducted 20 focus groups (N= 159) sampling from the community, patients, and caregivers of patients to identify attributions and thoughts on causality of mental illness among Jamaicans. The most common terms used to describe mental illness were "mad," "crazy," "mentally ill" and "head take you." Participants attributed the cause of mental illness to: 1) drugs such as "weed" marijuana; "ganga" crack and cocaine 2) biological causes (chemical imbalance from genetics and brain disorders); 3) psychological factors (stress, poor coping skills, "thinking too much," "studying too much," or worrying); 4) social factors, such as lack of support and maltreatment by others; and 5) religious or spiritual (supernatural) causes (such as Obeah and demon possession) (Arthur & Whitley, 2014). These studies though small in scope, show the depth and persistence over time of stigmatization of mental illness among Jamaicans and others in the Caribbean region.

Perception of Mental Illness Among Jamaican Diaspora and Their Children

Stigmatization of mental illness by Jamaican's is also documented among Jamaican diaspora. Research conducted over three decades in Britain shows that despite educational attainment, stigma related to mental illness was higher among the Afro-Caribbean and their children born in Britain (first and second-generation) (Tortelli et al., 2015). Yorke and colleagues (2014), reported that Jamaican immigrants and their off-springs continue to hold firm beliefs in Obeah--supernatural powers. Although not a research study, Ellis, (2015), documented the influence belief systems such as Obeah, have on "Jamaican Immigrants," and how Obeah is intertwined in the Jamaican belief system as it relates to "life, health, illness; as well as psychiatric conditions in the form of culture-bound syndromes; and lastly, help-seeking behaviors." He highlighted the case of a young man who became mentally ill after his family visited Jamaica. The family did not take their son to the doctor but claimed someone was jealous of their success and cast a spell on him "Obeah, necromancy." This misconception, led further deterioration and eventually homelessness of this young man (Ellis, 2015).

The cultural history of Jamaicans plays an integral role in their perception of mental illness (Hickling & Gibson, 2012; Kerr, 1963). Lack of cultural awareness could result in misdiagnosis, misunderstanding and or failed relationship between care providers, clients as well as families (Ellis, 2015). Jamaican American and their offspring in the United States may be experiencing or exhibiting signs and symptoms of mental illness, which if not treated, could lead to further mental and physical deterioration. Understanding Jamaican diaspora and first-generation Jamaican-Americans' perception of mental illness, factors contributing to the stigma of mental illness, and terms used by this population to describe mental illness is an important

step in understanding this group which may ultimately lead to improvement in care and better outcomes for all.

Perception and Attitude of Jamaican-Diaspora and 1st generation Jamaican-Americans towards Professional Help for Mental Illness

Despite prevalence of mental disorders among Jamaican-diaspora and first-generation Jamaican Americans, seeking professional help for mental illness symptoms is an ongoing concern. Although there is a scarcity of research on the lives of Jamaican-diaspora and their offspring related to mental illness in America, the few that are available, paint a gloomy picture. Yorke and colleagues (2016) surveyed 115 first-generation Jamaican immigrants in New York City looking at factors associated with their attitudes toward seeking professional mental health services. The results suggest that those who have strong family support, a negative attitude towards mental illness, and report psychological distress themselves tend not to report positive attitudes towards professional mental health services. Respondents reported the notion that it is taboo to divulge "mental illness" outside of the family even when there are obvious signs of psychological distress (Yorke et al., 2016).

The study findings reported that over 80% of the participants attributed stress, drug use, fate, bad nerves, studying too much, living in a bad neighborhood and other variables, as root causes of mental illness. A final important finding of this study, is the role of religion in the lives of this group; 63% viewed religion as important in helping their psychological needs (Yorke et al., 2016).

Conclusion

There is lack of understanding of Jamaican diaspora and first-generation Jamaican-Americans perception of mental illness and their interest and willingness to seek professional

health care. Some have chosen to continue to put their faith in religious leaders or engage in other mystic practices such as faith healers or "Obeah" ((Williams, 2013) instead of the healthcare system. Mental illness affects the patient, their family members, and society. There is a critical need to understand how Jamaicans who migrate to the United States and 1st generation Jamaican-Americans perceive mental illness. Research over the last 10 years addressing this segment of the population and general information is scarce. The findings from this proposal may provide a basis for the design of effective models to disseminate information about mental illness to this population to facilitate entry into the health care system for those with mental health illness and optimize outcomes for all.

Theoretical Framework

The Health Stigma and Discrimination Framework (Figure 1.) will guide this research to elucidate a deeper understanding of the drivers and the facilitators of mental illness stigma and help in identification of any intersection of socio-economic-demographic characteristics among Jamaican-Americans diaspora and first-generation Jamaicans. The Health Stigma and Discrimination Framework was developed to address stigma across various health conditions with the goal of contributing to research, intervention development, and policy proposal on health-related stigma (Stangl et al., 2019). It outlines the path of stigmatization relative to health, which may vary depending on location, culture, and socio-economic considerations. The framework points to factors that may contribute to stigma, how stigma is experienced, the relationship of policy and organizational behaviors to stigma and ultimately the social and health impact of stigma (Stangl et al., 2019; Stangl). The framework has five domains: 1) Drivers and facilitators of stigma such as demographic variables, behaviors and beliefs, and work and community characteristics that may support or negatively affect individual attitudes; 2) Stigma

Figure 1. Health Stigma & Discrimination: Permission to use framework granted by Dr. Stangl, 1/3/21

'Marking' which is the intersection of stigma towards a health condition along with demographic or occupational-related stigma; 3) Stigma Manifestations which include stigma experiences and stigma practices; 4) impact of stigma on the affected population, organizations and institutions; and 5) the health and social impacts of stigma (Stangl et al., 2019). This study will focus on the first and second domains in the framework: Drivers and Facilitators and Stigma 'Marking.'

A deeper and better understanding of the drivers and facilitators influencing Jamaican diaspora and first-generation Jamaican Americans' perceptions of mental illness will provide the data necessary to help direct development of interventions to decrease stigma and ultimately lead to improvement in seeking and accepting treatment.

Drivers and Facilitators of Stigma

The first domain addresses factors that drive or facilitate health-related stigma. Drivers of stigma are individual-level factors that have a negative impact on the stigmatization process (Stangl et al., 2013). For example, drivers of HIV-related stigma have been identified as: fear of

HIV infection through casual contact of people with HIV, concerns about productivity due to poor health from chronic conditions like HIV, and prejudice and stereotypes toward people with HIV or at risk for HIV (Mahendra et al., 2007; Stangl et al., 2019). One possibility that may impact people's perception of mental illness is how it is portrayed in the media. For example, people with schizophrenia are sometimes depicted as dangerous persons who should be kept at a distance (Corrigan et al., 2003; Link, 1987); mental illness may be implied to be a result of personal and/or family weakness (Jackson & Heatherington, 2006), and the media may perpetuate negative attitudes about the etiology of mental illness and its treatability (Arthur et al., 2010). Facilitators are society-level factors that influence the stigmatization process either negatively or positively (Stangl et al., 2013). Examples of facilitators for HIV-related stigma include cultural and gender norms, and structural barriers at the public policy. Some of the drivers and facilitators that may contribute to Jamaican-American and first-generation Jamaican-American perception of mental illness may be attributed to cultural heritage and beliefs system such as slavery, maladaptive coping skills, obeah, magic, sorcery, and witchcraft and/or punishment from God for wrongdoings as causes of mental illness (James et al., 2014; James & Peltzer, 2012; Kerr, 1963b). There are many stereotypes about mental illness among Jamaicans as well as social norms that get passed down through generations in story telling as well as observation from one's environment.

Other potential facilitators of the stigma of mental illness among Jamaican diaspora and first-generation Jamaicans is the over-reliance on **s**upport and guidance from family, which tends to take preeminence over seeking professional mental help further perpetuating the prevailing failure to discuss mental illness outside of the family setting (Yorke et al., 2016). Reliance on

family “kin support” both financially and emotionally is pervasive not only in Jamaica, but throughout the Caribbean (Forsythe-Brown et al., 2017).

Stigma ‘Marking’

Stigma ‘Marking’ is the application of stigma to individuals or groups based on specific health conditions or other perceived differences such as race, class, gender, sexual orientation or occupation (Stangl et al., 2019). For example, some people from the Caribbean view a child born with a birth defect as sin of parent or punishment from God, while others might believe dark skin individuals are inferior to lighter skin individuals (Arthur & Whitley, 2014; Kerr, 1963a). In this study I will be assessing Stigma ‘Marking’ specifically for mental illness and will examine association with select socio-demographic variables looking for an intersection between these variables and stigma towards mental illness.

While the Health and Stigma Discrimination Framework is new, it is appropriate to help us address the aims of this proposal. The framework emphasizes the social, cultural, political, and economic forces that are the building blocks and/or structures upon which stigma is based. It does not focus on stigma as an assignable thing which individuals impose on others (Stangl et al., 2019). Results of this study will enable me to discern if social, cultural, political, and economical forces contribute to stigma towards mental illnesses among Jamaican diaspora and 1st-generation Jamaican Americans. In testing the usability of this framework, I will be able to comment on the suppositions and if successful in examining stigma towards mental illness, support its intent to address stigma across varying health conditions.

Methods

Design

This study will use a cross-sectional survey design to assess Jamaican-diaspora in the United State of America and first-generation Jamaican-American's understanding and perception of mental illness and mental illness stigma as well as to determine the association of mental health stigma with mental illness knowledge and selected demographic variables. A cross-sectional design study is an appropriate method to address the specific aims of this study because it describes characteristics of a population and identifies predictors of outcomes. Data gathered in a cross-sectional study allows for statistical determination of variation in characteristics and traits across study participants who are assumed to be independent of one another (Stommel & Dontje, 2014).

Sample and Setting

The target population for this study is a convenience sample of Jamaican-diaspora and first-generation Jamaican-American, 18 years or older, living in the continental U.S for at least two years. Additional inclusion criteria are: able to read and write in English, access to the internet (via a computer, smartphone or tablet) to enable completion of the survey, and willingness to participate. There are no specific exclusion criteria.

Approximately 745,000 Jamaicans were living in the U.S. in 2017. The PEW Research Center reports that approximately 70% of Blacks over the age of 18 are on Facebook, 40% on Instagram, and 24% on LinkedIn (PEW Research Center, 2019). As the classification of blacks is complex, I will assume Jamaican-diaspora and Jamaican-Americans are included in these numbers. Taking a conservative approach, I estimate that approximately 30% of Jamaican-diaspora and 1st generation Jamaican-Americans over the age of 18 are on social media. This

means of the 745,000 estimated Jamaican-diaspora in the U.S. approximately 223,500 would be on social media, my target for eliciting participants in this study. To recruit participants for this study, I will ask Jamaican diaspora and 1st generation Jamaican-Americans that I know to post a flyer about my study on their social media platforms including Facebook®, Instagram®, LinkedIn®, WhatsApp® and Signal®. If necessary, to achieve desired sample size I will also ask that my contacts to email the flyer to their contacts.

According to Osman (Osman, 2020), the average Facebook user has approximately 338 'friends' with a mean of 200. If 15 of my contacts post my study flyer on their page, the potential pool of Jamaican diaspora and 1st generation Jamaican-Americans seeing my study flyer will be approximately 3000. According to ("SurveyAnyPlace," 2020), a typical response rate for surveys is approximately 33% which is considered good. In addition, a recent study on Jamaican immigrants looking at acculturation and dietary intake had a 64% response rate (Oladele et al., 2018). If I take a conservative approach and estimate a response rate of 10%, that would give me a potential sample size of 300.

Assumption	Sample Size Calculation for Specific Aim #3
Of the 745,000 Jamaicans living in the U.S., I will assume 30% of those over the age of 18 are on: Facebook®, Instagram®, LinkedIn®, WhatsApp® and Signal®; approximately 223,000 people. If I ask 15 of my contacts to post a recruitment flyer on their social media site, and each contact can connect to an average of 200 this will give me a potential pool of 3000 participants. If I take a conservative approach, and assume10% response rate I would have a sample size of 300.	Assuming a Type 1 error rate = .05 and 80% power I will be able to detect a Pearson correlation = 0.16 with an N of 300. For the categorical variables the detectable mean difference is 0.325 standard deviations when comparing 2 groups that are equally sized (N=150).

Procedures

The procedures for conducting this cross-sectional study, will be in accordance with the guidelines of the University of Massachusetts Medical School (UMMS) Institutional Review Board (IRB). IRB approval will be obtained before recruitment begins. I will ask a convenience sample of my contacts (~ 15) who are Jamaican diaspora or associate with Jamaican diaspora or 1st generation American-Jamaicans to post a recruitment flyer on their social media sites. Christopher Chaplin, (Honorary Consulate of Jamaica for the state of Pennsylvania) has also agreed to post the recruitment flyer on the Consulate of Jamaica in Philadelphia Facebook page where he currently has 506 followers (https://www.facebook.com/ConsulateJAPhilly/). Flyers for recruitment will initially be posted on social media websites and if needed, distributed via email-to-email contacts.

The recruitment flyer (Appendix A) will briefly describe the study and the inclusion criteria. Jamaican diaspora and 1st-generation Jamaican-Americans who are interested in participating can click on the link in the flyer which will bring them to a secure website to review the Fact Sheet, consent to participate and complete required surveys. A Fact Sheet (Appendix B) will explain the purpose of the study, procedures necessary, time commitment and the potential of minimal risk. Information on how data will be obtained and length of time to be stored will also be delineated. Contact information for myself and the IRB will be provided should anyone wish to speak with someone not associated with the study or have questions about rights as a research subject. Participation is voluntary and participants can stop or withdraw from the study at any time.

After reading the Fact Sheet people who would like to participate in the study will confirm their eligibility and if met will be directed to click a link that brings them to the surveys.

Completion of the surveys will indicate consent to participate. The surveys will all be of electronic format using the REDCap platform. No identifiable information will be requested: all study participant will be assigned a unique ID number. Anticipated time to complete the surveys is 30 minutes. All data will be collected anonymously and kept confidentially for research purposes at the university on a secured research drive at UMMS. After completion of the surveys all participants will receive the (*Substance Abuse and Mental Health Services Administration (2020).*) (SAMHSA's) National Helpline phone number (1-800=662-4357) and website: (https://www.samhsa.gov/find-help/national-helpline) for resources and support for anyone who feels a need or is interested.

Measures

Two survey instruments, the Prejudice Toward People with Mental Illness Scale (PPMI) (Kenny et al., 2018) (Appendix C) and the Mental Health Literacy Scale (MHLS) (O'Connor & Casey, 2015) (Appendix D) will be used to assess Jamaican diaspora and first-generation Jamaican-American's knowledge of mental illness, attitude towards mental illness, and any stigma associated with mental illness. In addition, participants will complete a researcher developed demographic form and an open-ended question asking about descriptors participants typically use or have heard others use in their lexicon to describe people with mental illness (Appendix F).

The Prejudice Towards People with Mental Illness Scale (PPMI) (Appendix C)

The PPMI is a 28 item scale developed to measure prejudice towards people with mental illness (Kenny et al., 2018). The scale consists of four subscales 1) fear/avoidance score: the sum of items 1-8 divided by 8; 2) unpredictability score; the sum of items 9-14 divided by 6; 3) authoritarianism, score; the sum of items 15-20 divided by 6 and 4) malevolence score as the

sum of items 21-28 divided by 8. The scale uses a 9-point rating from -4 (very strongly disagree) to +4 (very strongly agree). The psychometric properties of the PPMI consist of total prejudice score: the sum of all items divided by 28. Higher scores reflect greater prejudice. Cronbach's alpha = .91 for the total scale and for the four subscales .79, .82, .83 and .87.

The construct validity of the PPMI scale was based on correlation between 3 studies with diverse cultural groups, using the same 4-subscales, with different populations to arrive at the final 28-item scale. The PPMI scale and its subscales strongly correlate with the Community Attitudes toward Mentally Ill (CAMI) (Taylor & Dear, 1981). demonstrating concurrent validity.

The Mental Health Literacy Scale (MHLS) (Appendix D)

The MHLS is a 35-item developed to measure mental health literacy (O'Connor & Casey, 2015). The 35-items consist of 8 items addressing ability to recognize mental disorders; 4 looking at knowledge of where to seek information in need arise; 2 looking at knowledge of risk factors of mental illness and causes; 2 looking for knowledge of self-treatment; 3 knowledge of professional help available and the final 16 items gauged participants attitude in promoting and recognition appropriate help-seeking behavior. The attributes of MHLS are delineated in Table 1.

Table 1. Attributes for MHLS

Attributes	Operational Definition
Ability to recognize specific disorders	Ability to correctly identify features of a disorder, a specific disorder or categories of disorders
Knowledge of how to seek mental health information	Knowledge where to access information and capacity to do so
Knowledge of risk factors and causes	Knowledge of environmental, social, familial or biological factors that increase risk of developing a mental illness
Knowledge of self-treatment	

Attributes	Operational Definition
Knowledge of professional help available	Knowledge of typical treatments recommended by mental health professionals and activities that an individual can conduct. Knowledge of mental health professionals and the services they provide.
Attitudes that promote recognition and appropriate help-seeking	Attitude that impact on recognition of disorder and willingness to engage in help-seeking behavior

Adopted from: (O'Connor & Casey, 2015)

The scores of the MHLS range from 35 to 160; high scores reflect greater knowledge. The Cronbach's alpha for the MHLS is 0.873. Test re-test: $r = (69) = .797$, $p<.001$ (O'Connor & Casey, 2015). The MHLS is positively correlated with General Help-seeking Questionnaire (GHSQ) demonstrating construct validity. Methodological quality of MHLS was examined using the COsensus-based Standards for the selection of health status Measurement Instruments (COSMIN), an international Delphi study use to evaluate methodological quality of studies on measurement properties of health-related patient reported outcomes (Mokkink et al., 2010). The COSMIN has 11-questons on internal consistency; 5-questions on content validity (including face validity), and 10-questions on hypotheses testing (Mokkink et al., 2010). For the MHLS, six of the nine domains were determined as adequately assessed: 1) internal consistency, 2) reliability, 3) measurement error, 4) content validity, 5) structural validity, and 6) hypotheses testing (O'Connor & Casey, 2015).

This instrument is written at a high grade level so I will ask participants to rank the degree of difficulty overall that they had in understanding what the questions on this measure were asking.

Demographic Questionnaire (Appendix E)

A research developed demographic questionnaire will be used to collect data to describe participants and as well as provide additional data to support or refute potential facilitators and drivers of mental illness stigma described in the literature. Demographic characteristics of interest are: age, gender, education, employment, religiosity, years living in the U. S., socioeconomic status, and personal or family history of mental illness. In addition, to better understand the role of potential drivers and facilitators of mental illness stigma we will include a few items not included on the MHLS or the PPMI scale including beliefs about mental illness related to: drug or alcohol use, daily stressors, belief that mental illness is a spiritual/religious curse on the family, fear that those with mental illness are dangerous, belief that people with mental illness are unable to function in the work force, and role the media/television play in our understanding of mental illness.

Personal Descriptors of Mental Illness

Participants will respond to an open-ended statement eliciting the term(s) they use to describe mental illness or when referring to someone with a mental illness. Specifically, participants will be asked to respond to: Please type in the first 3 words you use or have heard other Jamaican Americans use when referring to or when describing people who have mental illness.

Data Management

All data will be collected online via REDCap and stored on an encrypted, password-protected server at University of Massachusetts Medical School. All collected data will be destroyed in five years. Each participant will have a unique identification number. No names or identifying information will be collected. All entries will be reviewed and examined for outliers and missing data.

Data Analysis

Data will be imported from REDCap into The Statistical Package for the Social Sciences (SPSS) Version 27 (SPSS Inc., Chicago IL) for statistical analysis. Descriptive statistics (frequencies, means, standard deviations, and percentages) will be calculated for all demographic and categorical variables. For continuous variables, mean, median, skewness, standard error of the mean, standard deviation, and histograms will be calculated. Study variables will be examined for outliers and systematic missing data. If data are not normally distributed, nonparametric tests will be performed. Cronbach's alphas will be computed for the MHLS and the PPMI.

***Specific Aim 1*:**

Describe U.S. dwelling Jamaican-diaspora and first-generation Jamaican-Americans knowledge of mental illness, stigma towards mental illness and agreement of drivers and facilitators of stigma proposed in the literature. In addition, participants will be queried as to their understanding of the terms and wordings of the items in the Mental Health Literacy Scale as it is written at a high grade level.

Descriptive statistics will be reported including central tendency (mean, median, and mode) as well as variability (standard deviation (SD), variance, and range) to summarize the data.

Specific Aim 2: Elicit descriptors used by U. S. dwelling Jamaican diaspora and first-generation Jamaican-Americans to describe mental illness. Content analysis will be used to describe the type and frequency of descriptors provided by study participants.

Specific Aim 3: Determine the association between mental illness stigma and mental illness knowledge, age, gender, education, employment, religiosity, years living in the U. S., socioeconomic status, personal history of mental illness, and family member with mental illness.

For the continuous variables, linear *regression* will be used to examine the relationships between mental illness stigma and mental illness knowledge, age, and years living in the US. T-test or Chi Square will be used to examine the difference in mental illness stigma scores and gender, education, employment, religion, SES, personal and/or family history of mental illness.

Protecting Human Subjects

This study will be reviewed by the University of Massachusetts Medical School Institutional Review Board (IRB). Conscious effort as well as ethical standards will be followed in every step of the research to protect participant's privacy, confidentiality and minimize risk. Informed consent will be obtained prior to enrollment and collection of any data. The Fact Sheet will be written in a manner that is understandable to participants. My contact information and that of the IRB will be provided should any participant have concerns or questions about the study.

Participants may withdraw from the study or refuse to answer all or part of the questions at any time. No physical harm is anticipated. The surveys ask about mental illness which may be a sensitive topic for some participants. All participant will have the researcher's email listed on the Fact sheet, should they have any question about the study or requested information. The PI is a licensed nurse practitioner with experience in mental health. All participants will be given the Substance Abuse and Mental Health Services Administration (SAMHSA's) National Helpline phone number (1-800=662-4357) and website (https://www.samhsa.gov/find-help/national-helpline) for resources and support for anyone who feels a need or is interested in information about mental health.

Limitations

As a cross-sectional study I will only be able to identify associations not cause-effect. Although social media has a potentially wide reach, the initial request for participants is limited to my contacts and their contacts. The validity of a few questions related to drivers and facilitators of mental health stigma have not been validated and thus the results will be considered exploratory.

Potential Challenges of this Study

One of the challenges that I might encounter during this research is low response rate. Although a large number of Jamaican-diaspora and 1st generation Jamaican-American are on social media, there is no evidence that they participate in surveys or use social media for such cause. If this occurs, I will institute a second recruitment approach by having my contacts send a direct email to their Jamaican diaspora and 1st generation Jamaican-American contacts inviting their contacts to participate. Lastly, I may have to consider an incentive if I have trouble recruiting. Another potential challenge is some of the questions might be a trigger for some participants: this trigger might result in unfinished survey completion. To mitigate this challenge, and achieve an acceptable response rate, I will initiate my second approach of solicitating my contact to use their emails to assist in distributing my flyer to help with recruitment. Lastly, the online nature of the surveys means I am relying on self-report for their perspectives and there may be an element of social desirability. To counter this concern, I am using valid and reliable instruments.

Conclusion

While stigma associated with mental illness is not specific to Jamaicans, Jamaican-diaspora and or 1st generation Jamaican-Americans; the long history of stigma and the cultural

norms of this group are complex and may contribute to persistent mental health stigma. Understanding current knowledge of and about mental illness, and the drivers and facilitators of any mental illness stigma among Jamaican-diaspora and 1st generation Jamaican-Americans will provide data that will help propel the next step to increase awareness of mental illness, recognition of signs and symptoms of mental illness, the acceptance of mental health diagnoses and utilization of mental health services among this population. The ultimate goal is to bring wider awareness of mental illness and to decrease stigma through increased knowledge.

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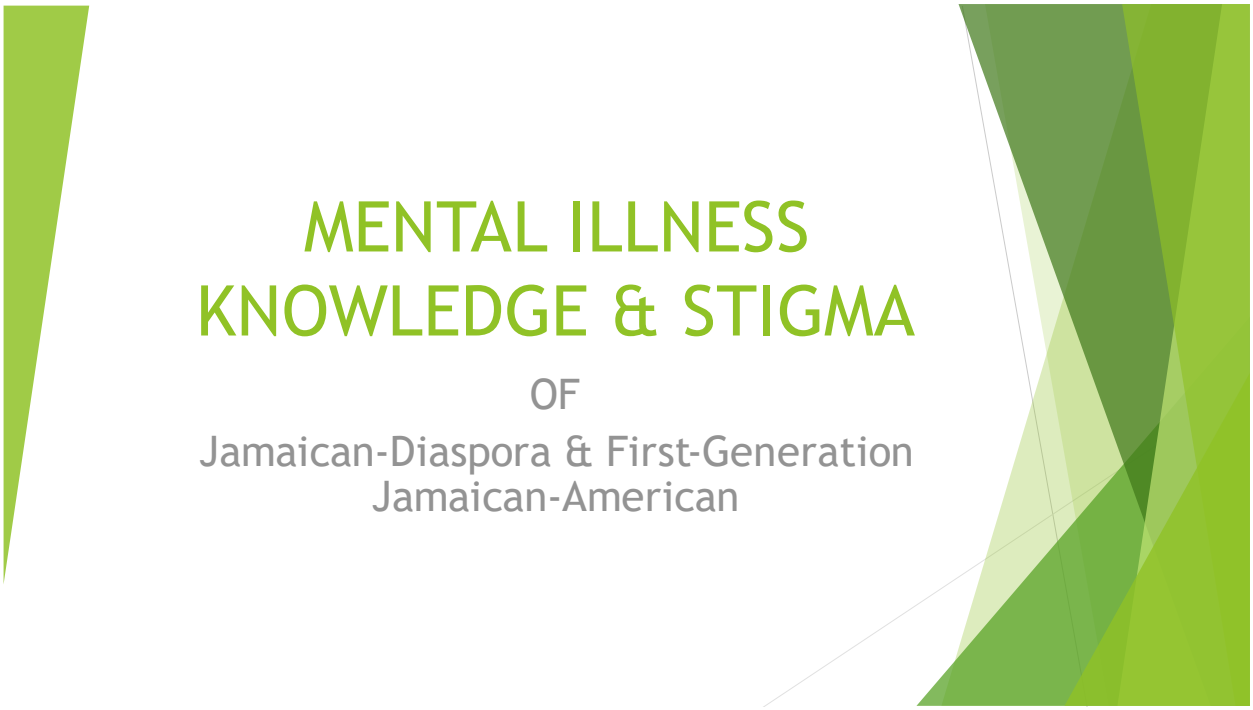
Summary of Changes from Proposal

Due to low response rate, permission was sought from IRB to do in-person recruitment in an attempt to achieve the proposed sample size.

Slide Presentation




Presented by
Rose Marie Nyakako
Tan Chingfen Graduate School of Nursing
UMass Chan Medical School

Stigma: Historical context matters

- Slaves brought to Jamaica from West Africa adopted a hybrid belief system in which the slaves' belief in supernatural powers and the slave master's belief in a monolithic God (Christianity) created a dichotomy of confusion for both parties (Pitman, 1926).
- Afro-Jamaican's experienced traumatic and negative psychological impacts of slavery and forced religion in the early 1700s which persists today.
- Slaves viewed as "tools of production" and thought to be "void of human feelings, emotions, and mental needs" leading to many of the inhumane ways in which slaves were treated and punished in Jamaica in the early 1700s (Hickling, 2019; Morrison et al., 2015).

Black immigrants have high mental illness

- Blacks from Caribbean and their children born in Britain (first and second generations) have psychotic disorders five times higher than those of British Whites (Tortelli et al., 2015)
- Caribbean men in US are more likely to be diagnosed with mood disorders than their African American counterparts (Robinson et al., 2021; Williams et al., 2007)
- Black immigrants in US have higher risk of having psychiatric disorders than those born in US (Williams et al., 2007)

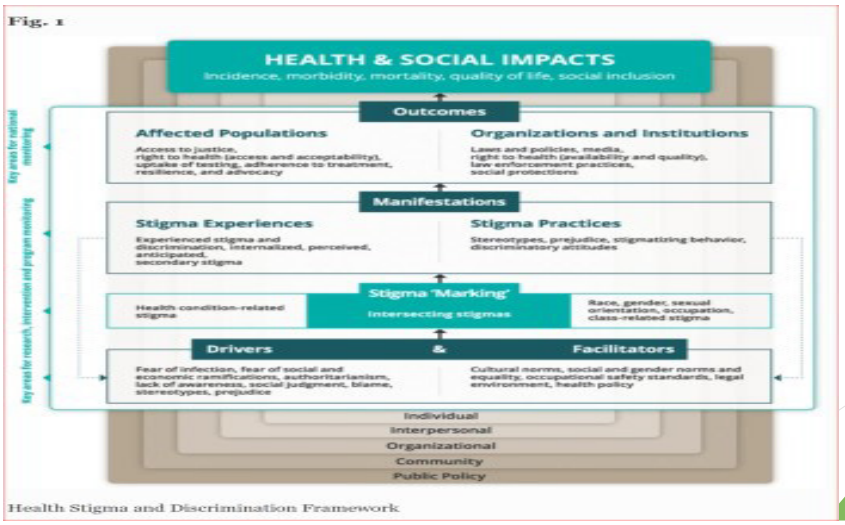
Mental illness stigma decreases engagement in health care

- Unwillingness to discuss mental illness or recognize it as a true medical condition contributes to stigma(Arthur et al., 2010)
- Attributing etiology of mental illness to obeah or drugs contributes to stigma (Ellis, 2015; Lacey et al., 2016)
- Refusing to address or acknowledge existence of mental illness as a health condition further contributes to stigma associated with mental illness (Corrigan et al., 2014).
- Above behaviors decrease engagement in mental health care (Parcesepe & Cabassa, 2013)

Specific Aims

1. Describe US Jamaican diaspora and first-generation Jamaican Americans' knowledge about mental illness and stigma toward mental illness, as well as their agreement with select drivers and facilitators of mental illness stigma proposed in the literature.
2. Elicit descriptors used by US Jamaican diaspora and first-generation Jamaican Americans to refer to ordescribe people with mental illness.
3. Determine association between mental illness stigmaand mental illness knowledge, age, gender, education, employment, religiosity, years of residence in US, socioeconomic status, and personal or family history of mental illness.

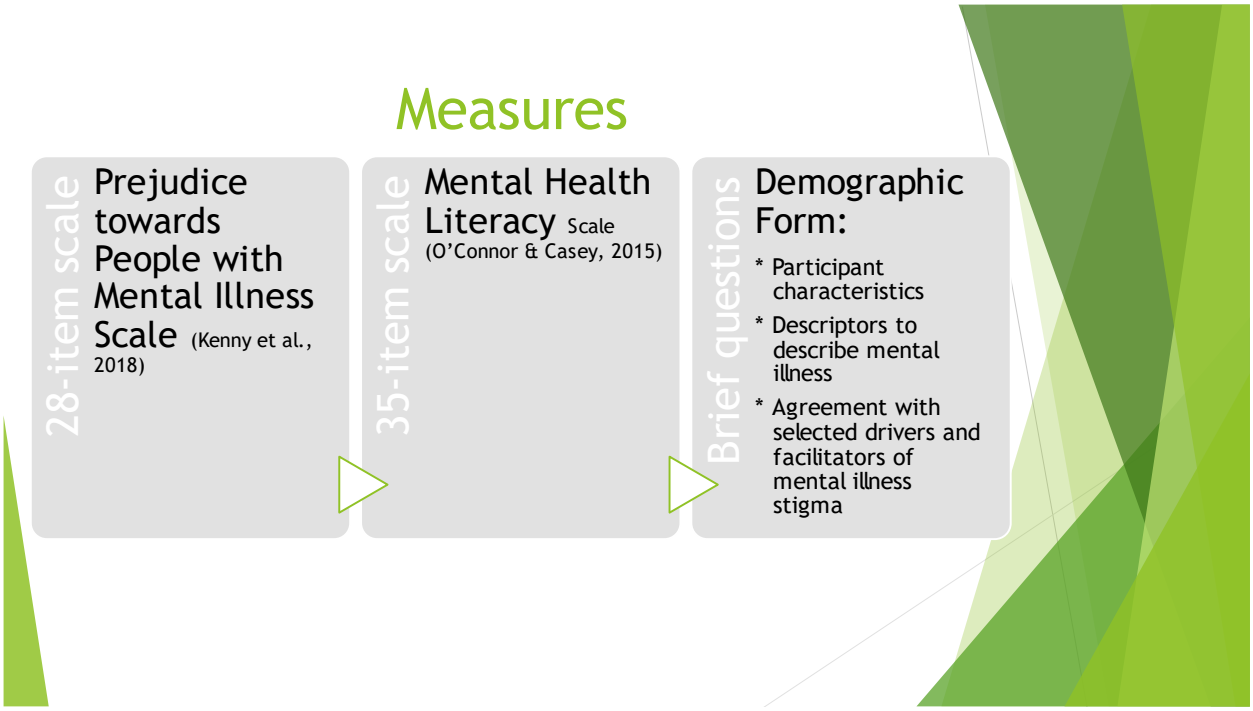
Health Stigma and Discrimination Framework (Stangl, 2019) guided this study.



Health Stigma and Discrimination Framework

This was a cross-sectional study using a convenience sample of Jamaican diaspora and first-generation Jamaican Americans

- Inclusion criteria: 18 years or older, living in US 2-years or greater, able to read and write English
- No exclusion criteria
- Recruitment took place across various social media platforms and in person
- Targeted sample size of 300 assuming a Type 1 error of 0.5, 80% power, and desire to detect a Pearson correlation of at least .16, a small effect size (Cohen, 1988)


Measures
28-item scale
Prejudice towards People with Mental Illness Scale (Kenny et al., 2018)
35-item scale
Mental Health Literacy Scale (O'Connor & Casey, 2015)
Brief questions
Demographic Form:
* Participant characteristics
* Descriptors to describe mental illness
* Agreement with selected drivers and facilitators of mental illness stigma

Participants (N=175) characteristics

Characteristic	Mean (SD)	Range
Age (years)	44.92 (14.3)	18-75
Years Jamaican diaspora in the US	27.72 (12.03)	2-53
	n	%
Gender		
Female	116	71.2
Male	47	28.8
Birth country		
Jamaica	124	72.9
United States	46	27.1
Marital status	159	100.0
Single	54	34.0
Married/partnered	93	58.5
Education		
≤HS	41	26.6
Associate degree	19	12.3
Bachelor's degree	42	27.3
Graduate degree	52	33.8

Primary Source of Support/Advice as It Relates to Mental Illness

	N	%
Family/friends	60	37.7
Counselor/therapist	30	18.9
Dr., NP, PA	29	18.2
Psychiatrist	22	13.8
Pastor/religious leader	14	8.8
Other	4	2.5

Knowledge of Mental Illness (MHLS)

Total Sample	Jamaican Diaspora	Jamaican American		Age < 40	Age ≥ 40	
Mean (SD) 99.08 (10.13)	Mean (SD) 97.25 (10.27)	Mean (SD) 104.27 (7.74)	P <.001	Mean (SD) 102.08 (10.95)	Mean (SD) 97.05(9.54)	P .003

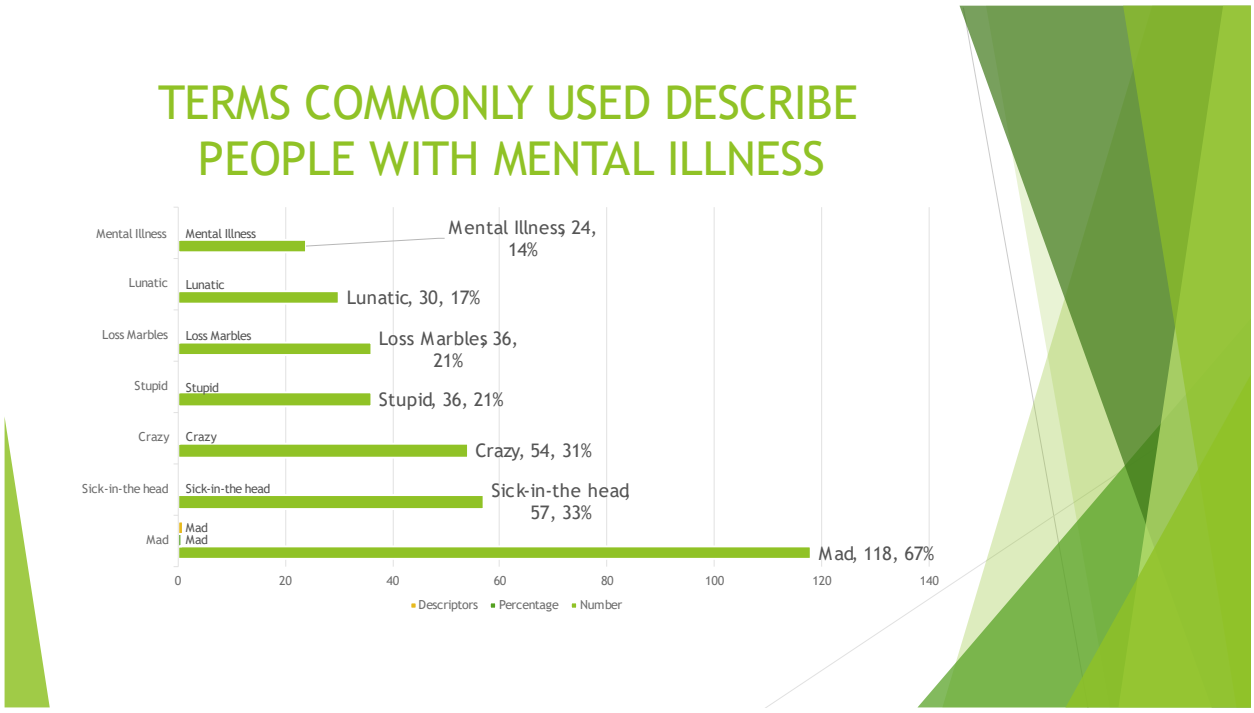
Stigma of Mental Illness (PPMI)

	Total Sample	Jamaican Diaspora	Jamaican American		Age < 40	Age ≥ 40	
	Mean (SD)	Mean (SD)	Mean (SD)	p	Mean (SD)	Mean (SD)	p
Mean PPMI	-0.67 (.80)	-.52 (.76)	-1.10 (.73)	< .001	-1.02 (.87)	-.48 (.69)	< .001
PPMI Subscales							
Fear Avoidance		-.20 (1.17)	-.99 (1.28)	< .001	-.89 (1.32)	-.16 (1.12)	< .001
Unpredictability		.91 (1.18)	.32 (.96)	.003	.52 (1.16)	.88 (1.15)	.06
Authoritarianism		.15 (1.39)	-.78 (1.30)	< .001	-.69 (1.46)	.25 (1.30)	< .001
Malevolence		-2.40 (1.12)	-2.50 (.81)	.59	-2.58 (.93)	-2.36 (1.06)	.19

Facilitators and Drivers of MI Stigma

Participant beliefs related to mental illness/mental illness stigma

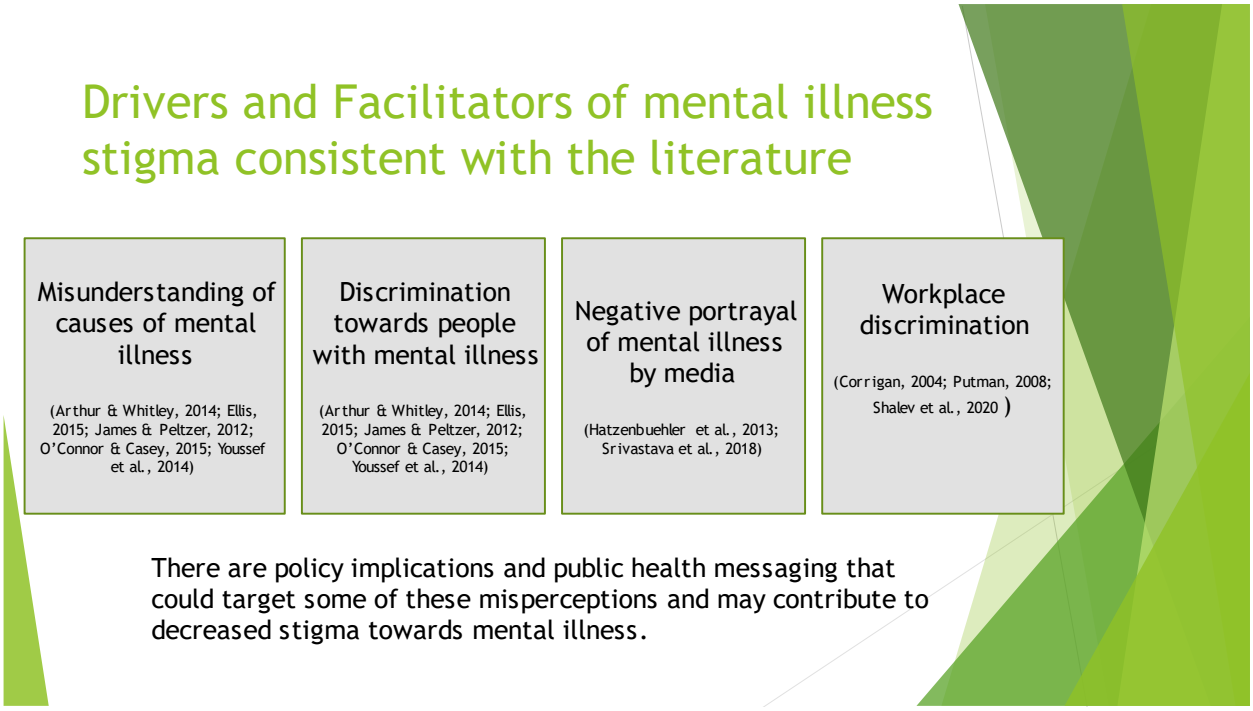
Cause of mental illness	Yes n (%)	No n (%)	Unsure n (%)
Disturbance of brain chemistry	126 (74.6)	10 (5.9)	33 (19.5)
Stressful life events	118 (70.2)	15 (8.9)	35 (20.8)
Traumatic brain injury	97 (57.7)	24 (14.3)	47 (28.0)
Stress from job or school	80 (47.3)	36 (21.3)	53 (31.4)
Marijuana, cocaine, ganga use	42 (24.7)	78 (45.9)	50 (29.4)
Alcohol use	35 (20.7)	82 (48.5)	52 (30.8)
Lack of will power	10 (5.9)	126 (74.6)	33 (19.5)
Punishment from God	2 (1.2)	146 (87.4)	19 (11.4)
Perceptions of mental illness stigma			
Aware of work discrimination towards people with mental illness	41 (24.6)	100 (59.9)	26 (15.6)
Persons with mental illness depicted as dangerous on news or TV shows	73 (44.0)	60 (36.1)	33 (19.9)


TERMS COMMONLY USED DESCRIBE PEOPLE WITH MENTAL ILLNESS
Mental Illness
Lunatic
Loss Marbles
Stupid
Crazy
Sick-in-the head
Mad
Mental Illness, 24, 14%
Lunatic, 30, 17%
Loss Marbles, 36, 21%
Stupid, 36, 21%
Crazy, 54, 31%
Sick-in-the head, 57, 33%
Mad, 118, 67%
0
20
40
60
80
100
120
140
Descriptors
Percentage
Number

Association of Mental illness Stigma to Knowledge and Personal Characteristics

- Positive correlation bet age & stigma towards people with mental (PPMI); statistically significant r = .29 (p.001)
- Males more stigma than females (p = .03); females more knowledge of MI than males (p = .001)
- Jamaican diaspora had significantly more stigma (p = .001) and significantly less knowledge (p = .001) than Jamaican-Americans
- Participants w/ personal diagnosis of MI had significantly less stigma than those w/o (p = .001)
- Having a family member with MI associated w/ less stigma (p = .006)
- Having friend with MI significantly associated w/less stigma (p = .002) increased knowledge of MI (p = .05)
- Number of years living in US was not associated with stigma

Discussion


Drivers and Facilitators of mental illness stigma consistent with the literature
Misunderstanding of causes of mental illness
(Arthur & Whitley, 2014; Ellis, 2015; James & Peltzer, 2012; O'Connor & Casey, 2015; Youssef et al., 2014)
Discrimination towards people with mental illness
(Arthur & Whitley, 2014; Ellis, 2015; James & Peltzer, 2012; O'Connor & Casey, 2015; Youssef et al., 2014)
Negative portrayal of mental illness by media
(Hatzenbuehler et al., 2013; Srivastava et al., 2018)
Workplace discrimination
(Corrigan, 2004; Putman, 2008; Shalev et al., 2020)
There are policy implications and public health messaging that could target some of these misperceptions and may contribute to decreased stigma towards mental illness.

Implications for Education, Research and Policy

- Lack of knowledge among participants suggests community education on causes, signs and symptoms, and treatment of mental illness are needed.
- Use of derogatory terms to describe people with mental illness suggests public health campaign on use of appropriate terms may be helpful.
- Participants with exposure to others with mental illness had decreased stigma raising questions and need for research on how to best share people's experiences.
- Work discrimination towards people with mental illness warrants further research and examination of workplace policies.

Limitations and Strengths

- Limitation: Convenience sampling and small sample size limits generalizability to broader populations
- Limitation: Unclear why 47% of those who consented to do the study did not completed survey
- Limitation: Over 50% of participants were college educated compared to general Jamaican diaspora of 21% having a bachelor's degree (Zong & Batalova, 2019)
- Strength: responses from several geographic areas tapping into different perspectives
- Strength: Inclusion of both Jamaican diaspora and first-generation Jamaican Americans reflecting perspective spanning 2 generations.

Among highly educated participants, efforts to reduce mental illness stigma still necessary

- Although there was low mental illness stigma overall, stigma persists and was higher among Jamaican diaspora compared to First-generation Jamaican Americans
- Negative use of derogatory terms to describe people with mental illness is common and a concern
- Increased knowledge of mental illness is associated with less stigma
- We need ongoing efforts to increase the public knowledge of mental illness with emphasis on appropriate word choice/terms to use when talking about people with mental illness.


Just a few acknowledgements before we break for questions and comments….

Honor, Glory, Praise & Majesty to the King of My Life! My Conductor! The God in Whom I Trust!

- You have made my mountains to stand strong; but during the darkest hours of my life, you never left me! I Love you Lord!
- Thank you for carrying me in the palm of Your hands! Please always remain with me!

Appreciation

- Dr. Morris
- Dr. Crawford
- Dr. Wassef
- Entire community of Tan Chingfen Graduate School of Nursing

My husband, children (Two of whom are here today, Rachel Atieno and Sarah Akinyi), my sisters (two of whom are here today), my brother-in-law Desmond, my niece and her husband who are also here, along with many nieces and nephews,

Church family two of whom are here today, the Morrisons.

Diane Quinn→ for helping me navigate Red Cap and other behind the scene support

Thanks for all the Support! I appreciate all of you**!**

In Memory of my Beloved Son
Juma Daud Nyakako
July 15, 1998 - May 7th 2022

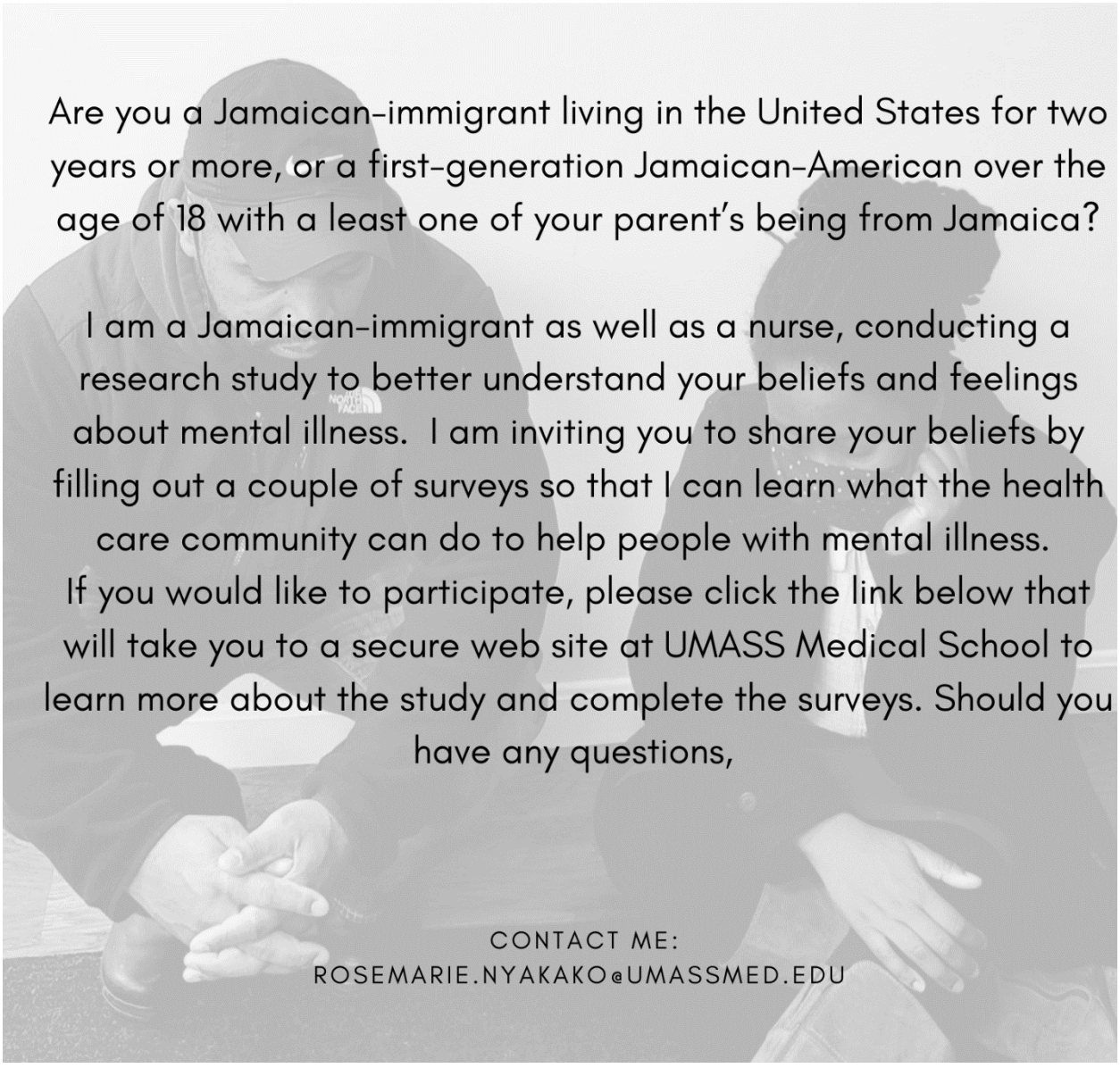
Thank you,

Any questions/comments ???

Dissemination Plan

The primary description of this dissertation work was submitted as a manuscript on 8th of February 2023 to the *Community Mental Health Journal* for review and consideration for publication.

Appendix A: Recruitment Flyer



Appendix B

UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL

COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN

RESEARCH FACT SHEET (January, 2021)

Title: Title Jamaican-Diaspora and First-generation Jamaican-American Perception of Mental illness

Investigator: Rose Marie Nyakako

Sponsor: Name Graduate School of Nursing

A. We are inviting you to participate in a research study.

B. Taking part in this research is voluntary and completely up to you. You are free to say no or to leave the research at any time.

C. The purpose of this study is to understand Jamaican-diaspora and first-generation Jamaican-Americans view of mental illness.

D. If you agree to participate, you will be asked to complete 2 surveys about mental illness, a survey that describes a little about you (like your age, gender, education), and to type in words you use to describe mental illness. This will all be done through a link on a secure web site and will take about 30 minutes...

E. You may feel some discomfort answering the survey questions about mental illness. You can skip any you don't want to answer. Resources and a phone number for the Substance Abuse and Mental Health Services Administration National Helpline will be provided should you feel the need for help.

   We will not ask any personal identifiable information about you and all recorded information will be anonymous. All data will be coded with a subject ID. We will keep all electronic information on secure computer networks. These computer networks have many levels of protection.

   The data you provide will be destroyed in 3 years.

F. At this time, we do not think that the research data will lead to commercial profit. In the event it does, there are no plans to share any financial gain with you.

G. Your participation may help us to gain knowledge about **Jamaican-diaspora and 1st-generation Jamaican-Americans views of mental illness**. However, there is no direct benefit to you.

H. We will try to limit access to your responses to people who have a need to review this information. We cannot promise complete privacy. The University of Massachusetts Medical School, including the Institutional Review Board (IRB) and research, and compliance offices, may see your information.

I. The University of Massachusetts Medical School does not provide funds for the treatment of research-related injury. If you are injured as a result of your participation in this study, treatment will be provided. You or your insurance carrier will be expected to pay the costs of this treatment. No additional financial compensation for injury or lost wages is available. You do not give up any of your legal rights by participating in this research.

J. If you have any questions, concerns, or complaints, or think that the research has hurt you, you can talk to the Principal Investigator: **Rosemarie.nyakako@umassmed.edu.** This research has been reviewed and approved by an Institutional Review Board. You can reach them at (508) 856-4261 or irb@umassmed.edu if you would prefer to speak with someone not associated with the study or have questions about your rights as a research subject.

Appendix C

The Prejudice Towards People with Mental Illness (PPMI) Scale Study ID _____

Instructions: The following items deal with various ways you may think or feel about people with mental illness. A mental illness or disorder is a diagnosable illness which significantly interferes with an individual's thoughts, emotions, behavior, and/or social relationships. There are many different types of mental illness including depression, anxiety, schizophrenia, and personality disorders.

Here we are interested in your views and beliefs about people with mental illness in general.

Please read each question carefully and answer as honestly as you can, using the following scale:

- 4	-3	-2	-1	0	1	2	3	4
Very strongly disagree	Strongly disagree	Disagree	Slightly disagree	Unsure/neutral	Slightly agree	Agree	Strongly agree	Very strongly agree

Score	
	1. I would find it hard to talk to someone who has a mental illness
	2. I would be just as happy to invite a person with mental illness into my home as I would anyone else. *
	3. I would feel relaxed if I had to talk to someone who was mentally ill. *
	4. I am not scared of people with mental illness. *
	5. In general, it is easy to interact with someone who has mental illness. *
	6. I would be less likely to become romantically involved with someone if I knew they were mentally ill.
	7. It is best to avoid people who have mental illness.
	8. I would feel unsafe being around someone who is mentally ill.
	9. The behavior of people with mental illness is unpredictable.
	10. The behavior of people with mental illness is just as predictable as that of people who are mentally healthy. *
	11. In general, you cannot predict how people with mental illness will behave.
	12. People with mental illness often do unexpected things.
	13. I usually find people with mental illness to be consistent in their behavior. *
	14. People with mental illness behave in ways that are foreseeable. *
	15. People who are mentally ill should be free to make their own decisions. *
	16. People who are mentally ill should be forced to have treatment.
	17. Those who have serious mental illness should not be allowed to have children.

	18. People who are mentally ill should be allowed to live their life any way they want. *
	19. People who are mentally ill need to be controlled by any means necessary.
	20. Society does not have a right to limit the freedom of people with mental illness. *
	21. We, as a society, should be spending much more money on helping people with mental illness. *
	22. People who are mentally ill are avoiding the difficulties of everyday life.
	23. People who develop mental illness are genetically inferior to other people.
	24. People with mental illness do not deserve our sympathy.
	25. People with mental illness should support themselves and not expect handouts.
	26. People who become mentally ill are not failures in life. *
	27. We need to support and care for people who become mentally ill. *
	28. Under certain circumstances, anyone can experience mental illness.

Appendix D

Mental Health Literacy Scale Study ID _____

The purpose of these questions is to gain an understanding of your knowledge of various aspects to do with mental health. When responding, we are interested in your degree of knowledge. Therefore, when choosing your response, consider that:

Very unlikely = I am certain that it is NOT likely

Unlikely = I think it is unlikely but am not certain

Likely = I think it is likely but am not certain

Very Likely = I am certain that it IS very likely

1. If someone became extremely nervous or anxious in one or more situations with other people (e.g., a party) or performance situations (e.g., presenting at a meeting) in which they were afraid of being evaluated by others and that they would act in a way that was humiliating or feel embarrassed, then to what extent do you think it is likely they have **Social Phobia**

Very unlikely Unlikely Likely Very Likely

2. If someone experienced excessive worry about a number of events or activities where this level of concern was not warranted, had difficulty controlling this worry and had physical symptoms such as having tense muscles and feeling fatigued then to what extent do you think it is likely they have **Generalized Anxiety Disorder**

Very unlikely Unlikely Likely Very Likely

3. If someone experienced a low mood for two or more weeks, had a loss of pleasure or interest in their normal activities and experienced changes in their appetite and sleep then to what extent do you think it is likely they have **Major Depressive Disorder.**

Very unlikely Unlikely Likely Very Likely

4. To what extent do you think it is likely that **Personality Disorders** are a category of mental illness.

Very unlikely Unlikely Likely Very Likely

5. To what extent do you think it is likely that **Dysthymia** is a disorder.

Very unlikely Unlikely Likely Very Likely

6. To what extent do you think it is likely that the diagnosis of **Agoraphobia** includes anxiety about situations where escape may be difficult or embarrassing

Very unlikely Unlikely Likely Very Likely

7. To what extent do you think it is likely that the diagnosis of **Bipolar Disorder** includes experiencing periods of elevated (i.e., high) and periods of depressed (i.e., low) mood

Very unlikely Unlikely Likely Very Likely

8.To what extent do you think it is likely that the diagnosis of **Drug Dependence** includes physical and psychological tolerance of the drug (i.e., require more of the drug to get the same effect)

Very unlikely Unlikely Likely Very Likely

9. To what extent do you think it is likely that in general among Jamaican , **women are MORE likely to experience a mental illness of any kind compared to men**

Very unlikely Unlikely Likely Very Likely

10. To what extent do you think it is likely that in general, among Jamaican American**, men are MORE likely to experience an anxiety disorder compared to women**

Very unlikely Unlikely Likely Very Likely

When choosing your response, consider that:

Very Unhelpful = I am certain that it is NOT helpful
Unhelpful = I think it is unhelpful but am not certain
Helpful = I think it is helpful but am not certain
Very Helpful = I am certain that it IS very helpful

11.To what extent do you think it would be helpful for someone to **improve their quality of sleep** if they were having difficulties managing their emotions (e.g., becoming very anxious or depressed)

Very unhelpful Unhelpful Helpful Very helpful

12. To what extent do you think it would be helpful for someone to **avoid all activities or situations that made them feel anxious** if they were having difficulties managing their emotions

Very unhelpful Unhelpful Helpful Very helpful

When choosing your response, consider that:

Very unlikely = I am certain that it is NOT likely

Unlikely = I think it is unlikely but am not certain

Likely = I think it is likely but am not certain

Very Likely = I am certain that it IS very likely

13.To what extent do you think it is likely that **Cognitive Behavior Therapy (CBT)** is a therapy based on challenging negative thoughts and increasing helpful behaviors

Very unlikely Unlikely Likely Very Likely

14. Mental health professionals are bound by confidentiality; however, there are certain conditions under which this does not apply. To what extent do you think it is likely that the following is a condition that would allow a mental health professional to **break confidentiality**:

If you are at immediate risk of harm to yourself or others

Very unlikely Unlikely Likely Very Likely

15. Mental health professionals are bound by confidentiality; however, there are certain conditions under which this does not apply. To what extent do you think it is likely that the following is a condition that would allow a mental health professional to **break confidentiality**: *if your problem is not life-threatening and they want to assist others to better support you*

Very unlikely Unlikely Likely Very Likely

Please indicate to what extent you agree with the following statements:

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
16. I am confident that I know where to seek information about mental illness					
17. I am confident using the computer or telephone to seek information about mental illness					
18. I am confident attending face to face appointments to seek information about mental illness (e.g., seeing the GP)					

19. I am confident I have access to resources (e.g., GP, internet, friends) that I can use to seek information about mental illness					

Please indicate to what extent you agree with the following statements:

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
20. People with a mental illness could snap out if it if they wanted					
21. A mental illness is a sign of personal weakness					
22. A mental illness is not a real medical illness					
23. People with a mental illness are dangerous					
24. It is best to avoid people with a mental illness so that you don't develop this problem					
25. If I had a mental illness, I would not tell anyone					
26. Seeing a mental health professional means you are not strong enough to manage your own difficulties					
27. If I had a mental illness, I would not seek help from a mental health professional					
28. I believe treatment for a mental illness, provided by a mental health professional, would not be effective					

Please indicate to what extent you agree with the following statements:

	Definitely unwilling	Probably unwilling	Neither unwilling or willing	Probably willing	Definitely willing
29. How willing would you be to move next door to someone with a mental illness?					

30. How willing would you be to spend an evening socializing with someone with a mental illness?					
31. How willing would you be to make friends with someone with a mental illness?					

	Definitely unwilling	Probably unwilling	Neither unwilling or willing	Probably willing	Definitely willing
32. How willing would you be to have someone with a mental illness start working closely with you on a job?					
33. How willing would you be to have someone with a mental illness marry into your family?					
34. How willing would you be to vote for a politician if you knew they had suffered a mental illness?					
35. How willing would you be to employ someone if you knew they had a mental illness?					

Question relating to the Mental Health Literacy Scale (MHLS): On a scale of 1-5, please rate how hard it was for you to understand what the questions in this survey meant.

1-Very hard, I didn't understand most of the questions

2-A little hard, I didn't understand half of the questions

3- Neutral, the questions weren't hard, and they weren't easy to understand

4- Not very hard, I understood more than half of the questions

5 – Not hard at all, I understood most of the questions

Appendix E

Demographic Form	Study ID: _____
What country were you born in?	United States Jamaica
If you were born in Jamaica, what year did you migrate to the United States?	
What state do you live in now?	
What is your age (years)?	
What is your marital status?	Single Married or cohabitating Divorced/Separated Widowed Prefer not to answer
With whom do you live?	Alone With husband/wife With spouse and children Other Prefer not to answer
Which gender best describe you?	Male Female Other Prefer not to answer

Demographic Form	Study ID: _____
What is your highest Level of education?	Less than high school diploma High school graduate or GED Associate degree Bachelor's degree Graduate degree Prefer not to answer
What is your employment status?	Not employed, not looking for work Not employed, looking for work 20 hours per week or less More than 20 hours per week Retired Disabled Prefer not to answer
What is your combined family income per year?	$0 - $26,200 $26,201 - $50,000 $50,001 - $100,000 $100,001 - $150,000 $150,001 - $200,000 Greater than $200,001 Prefer not to answer
Do you consider yourself a religious or spiritual person?	Yes No Prefer not to answer
Do you participate in religious services?	Yes I attend services weekly

Demographic Form	Study ID: _____
	I attend services monthly I attend services a few times a year No Prefer not to answer
Have you ever been diagnosed with a mental illness?	Yes No Prefer not to answer
Do you have any family members who have been diagnosed with mental illness?	Yes No Prefer not to answer
Do you have any friends who have been diagnosed with mental illness?	Yes No Prefer not to answer
If you were in need of emotional support, advice or guidance about your mental health to whom would you go for help? Check all that apply ranking order for whom you would seek help from 1st, 2nd, 3rd, etc.	_____ Family/friends _____ Pastor/religious leader _____ Doctor/Nurse/Physician Assistant _____ Psychiatrist _____ Mental health counselor/Therapist _____ Other _____ Prefer not to answer

Demographic Form	Study ID: _____
Do you believe mental illness is caused by use of marijuana, cocaine, or ganga?	Yes No Unsure Prefer not to answer
Do you believe mental illness is caused by alcohol?	Yes No Unsure Prefer not to answer
Do you believe mental illness is caused by disturbance of brain biochemistry?	Yes No Unsure Prefer not to answer
Do you believe mental illness is caused by lack of will power?	Yes No Unsure Prefer not to answer
Do you believe mental illness is caused by stressful life events?	Yes No Unsure Prefer not to answer
Do you believe mental illness is a punishment from God?	Yes No Unsure Prefer not to answer
Do you believe mental illness is caused from stress in school or a job?	Yes No Unsure Prefer not to answer
Do you believe mental illness is caused from a traumatic brain injury?	Yes No Unsure

Demographic Form	Study ID: _____
	Prefer not to answer
Has news or television programs led you to believe that people with mental illness are dangerous?	Yes No Unsure Prefer not to answer
Are you aware of any work setting in which people with mental illness were discriminated against or not hired?	Yes No Unsure Prefer not to answer

Appendix F

Personal Descriptors of Mental Illness

Please type in the first 3 words or phrase you use or have heard other Jamaican Americans use when referring to or when describing people who have mental illness.

1._____

2._____

3._____

Appendix **G**

Potential Drivers of Mental illness Stigma

Demographic variables	**Literature support**	**Measurement Data collection**	**Variable Type/Outcome**
Age		Demographic form	Continuous
Gender	(Jackson & Heatherington, 2006)	Demographic form	Categorical
Marital status		Demographic	Categorical
Number of years living in US (if diaspora)		Demographic	Continuous
Educational attainment (years)		Demographic	Categorical
Occupation		Demographic	Categorical
Socio-economic status (SES)	(Jackson & Heatherington, 2006; Lacey et al., 2016)	Demographic	Categorical
Education	(Lacey et al., 2016)	Demographic	Categorical
Lack of knowledge/Awareness	(O'Connor & Casey, 2015; Youssef, 2018; Youssef et al., 2014)	MHLS # 20	Categorical
Fear/Avoidance	(Kenny et al., 2018)	PPMI #s 1, 2, 3, & 4 (Fear and Avoidance scale: $\alpha = 0.87$	Categorical
Fear of economic ramifications	(Brown et al., 2011; O'Connor & Casey, 2015)	MHLS # 35	Categorical
Fear of being hurt by someone with mental illness; perceive them as dangerous	(Bennett & Stennett, 2015; Brown et al., 2011; Link et al., 1999)	MHLS # 23; PPMI #1, 3, 4	Categorical
Fear that mental illness is contagious	(O'Connor & Casey, 2015)	MHLS #24 PPMI #4	Categorical
Authoritarianism	(Kenny et al., 2018)	PPMI # 17, 18, 19	Categorical
Misunderstanding of etiology of mental illness	(Arthur et al., 2010; Arthur & Whitley, 2014; Ellis, 2015; James & Peltzer, 2012; O'Connor & Casey, 2015)	PPMI # 11 MHLS # 21, 22	Categorical (question will be frame using 5-point Likert scale as is laid out in MHLS and for PPMI the malevolence subscale, the same process will be use
Belief that excesses stress causes mental illness	(Angermeyer et al., 1988; Arthur & Whitley, 2014; Gómez-de-Regil, 2014;	Demographic	Categorical

	Yorke et al., 2016; Youssef et al., 2014)		
Belief that drug use (marijuana, crack, cocaine, ganga) causes mental illness	(Arthur & Whitley, 2014; Gómez-de-Regil, 2014; Yorke et al., 2016; Youssef et al., 2014)	Demographic	Categorical
Prejudice towards mental illness	(Corrigan, 2004; Hatzenbuehler et al., 2013; Kenny et al., 2018)	Total score of PPMI measure	Categorical on 9-point Likert scale
Potential Facilitators of Mental Illness Stigma			
Cultural norms		MHLS 20, 21	
Social judgement	(Link et al., 1999; O'Connor & Casey, 2015)	MHLS # 20	Categorical
Reliance on family support versus professional mental health professional support	(Taylor et al., 2017; Yorke et al., 2016) (Vaux et al., 1987)	Demographic	Categorical
Belief that mental illness is a spiritual/religious curse on the family/Obeah	(Arthur & Whitley, 2014; Bennett & Stennett, 2015; Ellis, 2015)	Demographic	Categorical
Belief that mental illness is a failure of will; the persons' own fault	(Jackson & Heatherington, 2006; O'Connor & Casey, 2015; Youssef et al., 2014) (Angermeyer et al., 1988)	MHLS # 21, 26 Demographic sheet	Categorical
Belief that mental illness should be treated by a religious leader before a health professional	(James & Peltzer, 2012; Yorke et al., 2016)	Demographic form	Categorical
Belief that mental illness is not a real medical illness	(O'Connor & Casey, 2015)	MHLS # 22	Categorical
Belief that mental illness can be managed without mental health professional help	(James & Peltzer, 2012)	MHLS # 27, 28	Categorical
Media with negative depiction of mental illness	(Hatzenbuehler et al., 2013; Link et al., 1999; Srivastava et al., 2018; "Trends In News Media Coverage Of Mental Illness In The United States: 1995–2014," 2016)	Demographic	Categorical
Work policies	(Corrigan, 2004; Shalev et al., 2020)	Demographic	Categorical