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Development of Mental Illness Stigma in Kibera: An Ecological Systems Approach

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Abstract

High rates of mental illness and suicide are prevalent among Kenyan youth, reflecting societal systems that are unable to provide the needed mental healthcare. In fact, mental illness is heavily stigmatised in Kenyan society, behaviours of which are already evident among children and youth. This study adds to the existing Kenyan mental health research by examining how mental illness stigma develops and is exhibited across various levels of Kiberan society (a slum in Nairobi, Kenya) , reflecting the nested social systems of development created by Urie Bronfenbrenner. Semi-structured interviews were conducted with Kiberan (ex)residents, including youth (n= 21) and Kiberan NGO workers, social workers and psychologists (n= 6). The findings reveal macro, exo, meso and microsystemic stigma, pointing to a complex web of cultural and societal factors influencing mental illness stigma development and thus also the wellbeing of youth in Kibera. Furthermore, the findings indicate the importance of stakeholder input in developing intervention strategies, as participants indicated various methods of developing resilience against mental illness (stigma) that can be implemented across different levels of society.

Keywords: mental illness, stigma, development, youth, Kenya

Hoge percentages van psychische aandoeningen en zelfmoord worden waargenomen onder de Keniaanse jeugd, wijzend op maatschappelijke systemen die niet in staat zijn de benodigde geestelijke gezondheidszorg te bieden. Bovendien rust er een zware stigmatisering op psychische aandoeningen in de Keniaanse samenleving; stigmatiserend gedrag is al te zien bij kinderen en jongeren. Deze studie voegt zich bij het bestaande Keniaanse onderzoek naar geestelijke gezondheid door de ontwikkeling van de stigmatisering van psychische aandoening die zich toont op verschillende niveaus van de Kiberaanse samenleving (een sloppenwijk in Nairobi, Kenia) te onderzoeken, waarbij modellen van systematische stigmatisering en de geneste sociale ontwikkelingssystemen van Urie Bronfenbrenner worden weerspiegeld. Semigestructureerde interviews werden gehouden met (voormalige) inwoners van Kibera, inclusief jongeren (n=21) en volwassenen (n=6). De bevindingen tonen macro-, exo-, meso- en microsysteemstigma aan, wijzend op een web van culturele en maatschappelijke factoren die invloed hebben op de ontwikkeling van stigmatisering van psychische aandoeningen en daarmee ook het welzijn van jongeren in Kibera. Bovendien geven de bevindingen het belang van input van belanghebbenden bij het ontwikkelen van interventiestrategieën, aangezien deelnemers verschillende methoden aangaven om veerkracht tegen stigma te ontwikkelen die op verschillende niveaus van de samenleving kunnen worden toegepast.

Trefwoorden: psychische aandoeningen, stigma, ontwikkeling, Kenia

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Introduction

Youth Mental Illness in Kenya

Over the past decade, Kenya has seen an alarming rise in suicide rates, with a 2021 study setting this number at 11 per 100 000 persons (World Health Organization, 2021), putting Kenya amongst countries with the highest suicide burdens (Ongeri et. al., 2023). The highest rates of suicide and suicidal ideation in Kenya are seen among youth aged 15-19 (Ndetei et. al., 2022; Ongeri et. al., 2022); these rates would be higher if they included the countless (attempted) suicides among youth that go unreported due to social, cultural and legal factors (Ongeri et. al., 2022).

Suicide rates are not just statistics: they reflect the severe circumstances endured by individuals that led them to take their life. The main risk factors found to be associated with suicide are history of mental illness, stressful life events, and interpersonal difficulties (Ongeri et. al, 2022). There is a high prevalence of mental illness among Kenyan youth, including anxiety disorders, posttraumatic stress disorder, major depressive disorder, and substance abuse disorder (Ndetei et. al., 2016; Mbuthia, 2018). Life events found to be risk factors for youth in Kenya include “child labour, physical punishment, HIV/AIDS related orphanhood, and exposure to post-election violence” (Ndetei et. al., 2016, p. 76).

Without proper care, childhood mental illness may “significantly derail psychosocial development” (DeLuca, 2020, p. 153). Youth that survive mental illness face consequences that extend far into adulthood, such as “mental illness in later life, limited educational achievement, violence, poor sexual health and substance abuse” (Getanda, 2017, p. 201). Furthermore, mental illness can be passed down through generations, and may thus decrease the quality of life not only for an individual but also for future generations (Atlas, 2023).

Mental illness can, with proper care, be overcome. However, the World Health Organisation (WHO) reports that in low and middle income countries (LMICs) such as Kenya, budgets for mental health care fall into the last 1% of the health budget (World Health Organization, 2018). This creates a lack of mental healthcare, both in terms of infrastructure, including training mental healthcare professionals, and psychoeducation among citizens. Furthermore, the existing mental healthcare facilities in Kenya are rarely sought out in proportion to the mental illness rates (Ongeri et. al., 2022), and often only when an individual's symptoms are so visibly severe that they are forcibly admitted to a psychiatric clinic (Kamau et. al., 2017). This indicates that there are barriers to seeking out and obtaining mental healthcare.

Development of Stigma Amongst Youth

One of the leading barriers found to inhibit help seeking behaviour is stigma (DeLuca, 2020). *Stigma* is defined as: "the unwarranted social devaluing of a person or group based on actual or inferred attributes […] comprised of the stereotypes, prejudices, and discriminatory behaviours that prevent individuals or groups from participating fully in society" (Ndetei et. al., 2016, p. 73). Mental illness stigma manifests itself differently in youth than adults (DeLuca, 2020; Heary et. al., 2017; Mueller et. al., 2016). For the purpose of this paper, 'youth' will refer to all those under the age of 25, as this guideline is also used in other mental illness research in Kenya (Mbuthia et. al., 2018). When necessary, the term 'child' will be used to indicate those under the age of 18, the legal age of adulthood in Kenya (Ongeri et. al., 2022).

Stigmatizing attitudes and behaviour are observed in children as young as seven (DeLuca, 2020). These include labelling, in which persons with psychiatric symptoms are considered "bad"(Adler and Wahl, 1988 in DeLuca, 2022) or "crazy" (Spitzer and Cameron, 1995 in DeLuca, 2020, p. 156), terms that cause "fears of unpredictability and dangerousness" (DeLuca, 2020, p. 156). Negative attitudes towards individuals with a mental illness are also observed from an early age,

leading to significant social distance taken from persons with the above labels compared to those labelled as 'normal' (DeLuca, 2020; Ndetei et. al., 2016).

Stigmatizing attitude and behaviour increase in severity as youth increase in age. Stigma in adolescence is seen to include "social exclusion, hurtful treatment, and reduced expectations" (Heary et. al., 2017, p. 2950). Perceptions include seeing "affected people as being less intelligent, less trustworthy, less employable, and less favourable as romantic partners" (Ndetei et. al., 2016, p. 74). Behaviour exhibited by older youth and adults towards those with mental illness in Kenya may be extreme, specifically including "abuse, [exclusion] from education, and […] harsh physical punishment such as physical restraint or being locked in the house" (Ehiemua, 2014, p. 2057).

Negative connotation around mental illness also increases self-stigma: "young people [have] significant concerns about what others might think of them if they were to seek help" (DeLuca, 2020, p. 161). Getanda et. al. (2017) indicated that "[Kenyan] children with mental distress did not 'want to share' because of 'fear,' reflecting a similar attitude.

Gaps in the Understanding of Stigma Development

Current stigma research consists mainly of global North studies, with little research being done in LMICs and minority groups (Mueller et. al., 2016). However, different socio-cultural practices will result in different manifestations and developments of stigma. For instance, a study by Kyeii et. al. (2014), found that negative perceptions of mentally ill persons in Ghana are highly correlated with belief in supernatural forces, whereas spiritual beliefs are rarely mentioned in global North stigma research (DeLuca, 2020). Thus, though current research gives an indication of stigma behaviour and attitude patterns, the socio-cultural factors that influence stigma development and manifestation are still under researched (Chandra and Minkovitz, 2007; DeLuca, 2020; Heary et. al., 2017; Mueller et. al., 2016).

The current rise in suicides and attempts in Kenya is illuminating sociocultural factors that influence stigma development. For instance, lawyer and government expert Ochieng and Kamau

(2021) present “A Case for Urgent Reform” of the Kenyan penal code, indicating that mental illness stigma is held up by Kenyan law, where according to Kenyan Penal Code 226, “any person who attempts to kill himself is guilty of a misdemeanour,” punishable by incarceration. This has prompted Kenyan newspaper headlines such as: “Breaking the Chains of Stigma: The Unconstitutional Criminalization of Attempted Suicide in Kenya” (Rongoma, 2023), indicating the societal need for research that focuses on Kenyan stigma development – and how to ‘break the chains’ it has put so many in.

Though there are various Kenyan research studies indicating the importance of decreasing stigma to improve overall wellbeing (Mbuthia, 2018; Ndetei et. al., 2016; Ongeri et. al., 2022), no study has researched Kenyan sociocultural factors contributing to mental illness stigma. Thus this paper aims to contribute to LMIC research on stigma development, integrating prior youth stigma development knowledge with data obtained from Kenyan literature and the participants of the current study.

Kibera

This research will investigate the factors that contribute to youth stigma development in Kibera, a large unacknowledged slum in Kenya’s capital city Nairobi (Majale, 2008). Between 170,000 and 1.2 million people live in the 2.5 square kilometres that make up Kibera (*Kibera: Always deprived but rarely depressed,* 2020). Kibera has among the highest suicide and mental illness rates within Kenya, with the latter being as high as 45% of the population (Kamaru et. al., 2017; Mutiso et. al., 2018). Decreasing stigma is an important step to decreasing the burden of mental illness and increasing quality of life in Kibera.

Research Aim

In order to determine how ingrained this stigma is, and thus where to intervene in such a way that interventions target stigma development as holistically as possible, it is important to understand the stigma at each level of society, and how these influence and stimulate each other. This data will

be gathered qualitatively through interviews, in order to allow for Kiberan stakeholders to share their lived experiences and provide space for their ideas on interventions. This is done to counteract that "problematically, interventions that do exist either lack robust evidence-base or have been translated from high income countries (HIC)" (Getanda et. al., 2017, p. 202). Prior research has shown that "programmes targeting child mental health problems in LMICs should be planned in relevant and culturally appropriate ways. To achieve this, it is necessary to first understand the strengths, barriers and relevant cultural issues from the local community perspective" (2017, p. 202). Thus, this study aims to gain relevant sociocultural information that answers the following research question:

What are the factors contributing to the development of mental illness stigma among youth in Kibera, and how do these impact their well-being and access to mental healthcare?

Theoretical Framework

Ecological Systems Theory and Models of Stigma Development

This research will integrate youth stigma development research and findings of the current study using the bioecological systems theory introduced by Urie Bronfenbrenner and later updated by Bronfenbrenner and Morris (1979, 2005, 2007). This theory consists of four elements: person, process, context and time. The *person* introduces their characteristics into a context, such as age, and gender (Kitchen et. al., 2019), but also their psychological features and life experiences (Dobson and Douglas, 2020).

Context is modelled by nested societal systems that interact with the individual and each other (Dobson and Douglas, 2020). The first of these is the microsystem, "activities, roles, and interpersonal relations experienced by the developing person in a given setting" (Bronfenbrenner, 1979, p. 22). This is followed by the mesosystem, comprising "the interrelations among two or more settings in which the developing person actively participates" (Bronfenbrenner, 1979, p. 25). Within these levels, stigma is observed primarily through discriminatory behaviours and cognitions in interpersonal settings (Yang et. al., 2007).

Research on mental illness stigma development predominantly focuses on micro and mesosystemic actors, creating social-cognitive models that view the "individual sufferer […] as the primary locus in which stigma processes take place" (Yang et. al., 2007, p.1526). However, this conceptualisation is limiting (Corrigan et. al., 2004; Yang et. al., 2007). Though individual behaviour and cognitive processes are important in understanding stigma development, such models ignore that "some forms of prejudice and discrimination arise at the level of the institution, and reflect economic, political, and historic forces" (Corrigan et. al., 2004, p. 489). Thus, this research will include exo and macrosystemic factors to create a more holistic overview of stigma development within Kenyan culture.

The exosystem consists of "settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person" (Bronfenbrenner, 1979, p. 25). The most distal system is the macrosystem, relating to consistencies in culture, ideology, or wider factors (Kitchen et. al, 2019). Structural discrimination may be *intended,* in which exo and macrosystemic actors purposefully restrict opportunities of mental illness (Corrigan et. al., 2004), such as creating laws that criminalise or restrict mentally ill persons (Ongeri et. al., 2023). It may also be *unintended,* in which the consequences of policies that are not intended to discriminate still hinder those with mental illness (Corrigan et. al, 2004). For instance, allocating less money to research and treatment in the psychiatric domain (2004).

Process links person and context, they "operate over time and are posited as the primary mechanisms producing human development" (Bronfenbrenner and Morris, 2007, p. 795). Lastly, *time* relates to the "historical and cultural events… as well as social and biological transitions that shape an individual's experience" (Kitchen et. al., 2019, p. 490).

According to Bronfenbrenner (2005), use of the bioecological model needs to include at least the context, personal characteristics, and processes of development. Together, these factors create a

holistic overview of an individual's behaviours. Furthermore, such an approach reflects the cultural and societal norms in Kenya, which functions as a collectivist culture and may thus present behaviours and development differently than global North cultures (e.g. Keller, 2021). Due to limits of this thesis, I will focus particularly on Bronfenbrenner's context, integrating both social-cognitive models and structural discrimination models of stigma development. Personal characteristics, process, and time will be integrated where relevant.

Methods

Researcher Positionality

In order to conduct interviews and analyse these in a culturally sensitive manner, literature regarding international (child) development was consulted, predominantly written by global South persons[1]. Though this literature is not referenced it has a large influence on how this study was conducted. Being of global North origin, there are inherent biases I take with me into my work; I aim to make my own views as negligible as possible, focusing instead on the views of stakeholders interviewed, and the referenced literature. The latter is predominantly written by Kenyan researchers and scholars, for the afforementioned reasons.

Semi Structured Interviews

The data for this research was gathered using semi-structured interviews with 27 participants. Semi-structured interviews have been used in mental health research in the Kenyan context before, and are found to "encourage the exploration of experiences within the conceptual framework used" (Mbuthia et. al., 2018, p. 3); thus, this method of data collection was deemed fit for the current study. The purpose of the semi-structured interview was not only to acquire answers to questions about mental illness stigma in Kibera, but also to allow participants to be active

[1] See: Ansel, 2016; Thiessen, 2023

stakeholders in this research, guiding the direction of the research to topics that are important to them.

Due to contextual difficulties five participants opted to do an interview together. The same interview structure was followed, and participants were encouraged to answer each question individually if applicable and willing.

The interview questions asked about personal perceptions of mental illness in the Kiberan community, and opinions on mental illness intervention methods (see Appendix 1). The questions and methods were approved for use on vulnerable groups, including children, by the Utrecht University Board of Ethics.

Interview Procedure

Participants were informed about the research and given consent letters to sign before partaking in recorded interview. Upon completion of the interview, participants were given the chance to debrief due to the sensitive nature of the topic. The debriefing was done by myself, the researcher, after being informed by a Kiberan psychologist on how to provide culturally appropriate guidance. Audio recordings were transcribed, after which the audio files were deleted and the transcripts anonymised.

Participants

The 27 participants for this study were predominantly sampled through the Uweza Foundation, an NGO working in Kibera. The majority of youth that participated are part of Uweza programmes (n=17). Other youth participants were recruited from a rehabilitation centre for street children in Kibera (n=4). Additionally, participants included Uweza employees (n=4), a social worker (n=1) and a psychologist (n=1). Participant specifics are kept anonymous, see figure 1 below for basic descriptive information.

Table 1

Descriptive Information of Participants

Participant	Age	Sex	Occupation
1	18	F	student
2	30	F	journalist
3	18	F	student
4	15	F	High School (HS) student
5	25	M	artist
6	15	F	HS student
7	18	F	student
8	16	M	HS student
9	17	M	HS student
10	18	M	HS student
11	17	M	HS student
12	16	M	HS student
13	18	F	post HS
14	31	F	psychologist
15	32	M	NGO employee
16	17	F	HS student
17	18	F	student
18	18	F	HS student
19	18	M	HS student
20	16	M	N/A
21	15	M	N/A
22	27	M	social worker
23	16	M	HS student
24	39	F	NGO employee
25	21	M	football player
26	18	M	football player
27	20	M	student

Data Analysis

A thematic analysis approach (as defined by Braun and Clarke, 2006) was used. Braun and Clarke propose two approaches to thematic analysis: a 'Big Q and Small Q' approach. The 'Big Q' is used in this study, which uses no pre-set codes, with these instead being identified in a "bottom up" approach of the data (Braun & Clarke, 2006). The findings were then structured around themes found during analysis. Some examples of open codes that emerged from the data included: personal mental illness experiences, shame among men, and what NOT to do in interventions. The collected data was transcribed and analysed using the software Nvivo.

Findings

Experiences with Mental Illness

Out of the twenty-seven participants, thirteen indicated previously or currently struggling with mental illness. Seven participants knew (of) someone who had committed suicide. Furthermore, twenty-five participants indicated knowing one or more individuals with mental illness.

Some participants gave detailed accounts of their own mental illness struggles, including depression and suicide, "I come from a background where I've experienced like a lot of mental health issues myself… [like] depression and suicidal ideations" (participant 14), and trauma and abuse, "when I was young I saw my father beating my mother, and that memory still keeps haunting me… mental illness it hits you" (participant 26). Other participants opted not to discuss their own mental health difficulties.

Most participants were willing to discuss other's mental illness struggles, including those faced by their guardians*:* "My dad seemed to… have like an anti social personality disorder… and then my grandma cause we also lived with my grandma, my grandma also seems to have some kind of personality disorder" (participant 14); mental illness seen in friends*:* "I lost a friend… They had mental breakdown, and passed away" (participant 2); and struggles faced by community members*:* "You see

a boy, boys, young boys, they have committed suicide and you wonder, God, he was seven years" (participant 15).

Drug Abuse

Over half of the participants mentioned knowing someone that abuses drugs; when asked to define mental illness, thirteen participants indicated drug abuse to be the defining characteristic. The main reaction to those taking drugs is avoidance: "Most of [my friends] are taking bang, because they always see others taking it so they adapt to the culture of taking it… sometimes we try to avoid them, because it also affects us," (participant 19).

Participants gave various reasons for why someone may develop drug addiction. Though some indicate not understanding why addiction occurs, expressing disdain or pity, while others exhibit more understanding. For instance: "a lot of young people, if they're not going mad, they start engaging in illegal activities just to repress their mental illness.. they are [trying to find] something that will give comfort, at least temporary" (participant 2). Those that mentioned such reasons for taking drugs exhibited less disdain for drug users, indicating the importance of attribution in the development of stigmatizing behaviour.

Risk factors Contributing to Stigma Development

Culture of Shame

Language with Shameful Connotations

During the interview process, I was advised by Kiberan residents not to use the term 'mental illness' as it would prevent participants from sharing. A Kiberan psychologist mentioned that in Kiswahili she uses words that mean "someone who's not, you know, feeling well…. because that's more friendly… it takes away a lot of the shame" (participant 14). This is because the Kiswahili word for mental illness is 'uendawazimu', which translates to 'mad person' (participants 2, 15, 24). Words used during interviews to describe mental illness included: 'mental,' 'mad (person),' and 'diseased.'

Thus, shame around mental illness is seen in the language used to describe the mentally ill – both in Swahili and English.

(Fear of) Rejection of Mentally Ill Persons

Participants indicated that mentally ill persons are often rejected. Children with obvious mental illness are hidden (participant 15). Youth are taught to be careful: "you cannot get close… to these mad people running the streets" (participant 2). Among adults "people are ostracized because they're struggling" (participant 24).

Participants were asked to share their own experiences with mental illness, and though most did, many showed reluctancy to do so. For some participants, the interview was their first time opening up about suffering mentally. This was in some cases due to me, the interviewer, being an outsider: "If I was talking to someone close to me, I would not tell him what I have told you now, but you see I'm talking to you cause I don't know you and you don't me, so I am more free" (Participant 8).

One interview was done with a small group, which hindered some participants from speaking as freely as others had done: "maybe I was supposed to say something about myself, but you see we are many. So now, I can see like, I can speak it out, someone else will sneak it out, and give it to someone else" (participant 12). The group interview showed in real time that the fear of speaking up is social in nature: "We cannot discuss… so say I come to you, and tell you that it's not right, he's not ok. Then you see your brother, and tell him the opposite of what I said" (participant 26).

Rejection of Mental Illness Among Men

The research indicates a larger stigma around men experiencing mental illness than women. Men are specifically taught that mental illness is shameful: "You are a man. Don't cry … so growing up with that it's in your subconscious mind … an emotion comes, you block it, immediately. It's unacceptable" (participant 15). This behaviour is modelled during childhood and explicitly taught

during puberty, “that's when [boys] start to learn to be ashamed … that's when they learn they should walk like a man and talk like a man” (participant 14).

These learned behaviours thus negatively impact the help-seeking behaviour of men, but are also seen to inhibit gaining knowledge about mental illness as a topic. Male participants indicated they would not go to programmes specifically designed to educate about mental illness: “The ladies will come. All of them will be there. But no boy. So if you want to get them … be creative, introduce that mental health programme in that activity” (participant 15).

Race and Class: Mental Illness is for White People

Over half of the participants indicated struggling with *stress,*[2] notably financial stress. Younger participants mention lack of school fees as a major stressor, and older participants focus on all aspects of financial insecurity: “if you just find someone stressed somewhere, or someone left a note after suicide, it was they were struggling financially” (participant 5). It is important to note that such poverty is maintained by rising issues of unemployment in Kenya; “so you find most young adults or even adults get frustrated because of the fact that they have no jobs, but they have the papers, education papers” (participant 5). Children feel the effects of this unemployment too: “my father… lost the job, so I had to stay at home for some time, I can’t say we were chased out of school, but we were sent for school fees” (participant 4).

Most Kiberans have normalised this stress: “I been bred in a society where someone will be stressed, and say it is something normal, because maybe it is something that he she is used to hearing every day since they were kids” (participant 26). Stress being a type of mental illness is, in fact, considered a ‘white people problem,’ (participants 1, 2, 24) “as [we Kiberans are] just suffering, which is not depression” (participant 2). This has led to seeing those in Kibera with mental illness as weak, “we can be strong enough to handle things… we move on regardless” (participant 17), and

[2] Sometimes described as *pressure* rather than *stress*

seeing a therapist is considered a "luxury for white people" (participant 24) because it is not something that is part of the race and class Kiberans are born into.

Lack of Safety and Security

Participants indicated that mental illness is not taken seriously on a governmental level, and thus there is no promotion of protective factors against it. These factors would include, among others: "decent work, quality education, and safeness in our neighbourhoods" (participant 5).

Kibera does have several government institutions dedicated to safety. Through interviews conducted with youth at a street boys rehabilitation centre, it was observed how the quality of life there reflected the ignorance of mental healthcare in government facilities. One of these youth mentioned "Life here is not easy. [We] are being beaten, insulted, [we] are being abused" (participant 21). This view is shared by most of street children interviewed[3]. Without governmental regulation that protects the physical and mental healthcare at such institutions, the youth here grows up with the idea that they "must persevere, because men persevere" (participant 23). Thus, governmental institutions may perpetuate shame and suffering rather than prevent it[4].

Lack of Mental Health Policy

Kibera lacks policies that advocate for mental health care. The only policy mentioned is that of illegal suicide, which, regardless of whether participants see it as a just policy, is indicated to be too late of an intervention and contributing to stigma (participant 5). There is a need for mental healthcare in the form of safe spaces and open communication about this topic: "these people are suffering but there's no safe space for them to do this" (participant 2) and "[they] are suffering with depression, stress, but [are] not willing or free to open up about the situation. That's why you

[3] One participant disagreed, saying the institution was good compared to his home situation.
[4] This may not be true for every governmental institution in Kibera, however, no participant mentions being pleased with the existing facilities.

normally find the cases of suicide in the ghetto are very high" (participant 22). However, it is evident that currently "the government is blind to the issue [of] mental health" (participant 5).

Lack of Mental Health Education

The lack of government involvement in mental health care is additionally seen in a lack of education or awareness programmes, increasing stigma due to ignorance or misinformation. Public schools in Kibera follow the government mandated curricula, "the classes are probably 50 to 90 kids with one teacher, and they're all just cramming for these exams" (participant 24). These exams are extremely important, determining the future of the individual. Thus, the curriculum sees no space (or need) for topics such as mental health education. However, the set-up of this system also causes mental health issues, noted by participant 18: "she [decided] to repeat [her exam] so that she can get a better mark … she fails, so that leads to a mind that will go and commit suicide, because she had failed more than expected."

Resilience Factors

Personal coping mechanisms

Several participants mentioned having ways to decrease feeling bad about their own experiences or feelings. Participants 13 and 17 use different forms of art to release such tension, dancing and drawing respectively. "I knew how to deal with it, because I had started doing art when I was younger and then as I grew I still did it… that was helpful, because I wouldn't talk, but I would draw" (Participant 17).

For others, knowing what it is they are going through increased their resilience against stigma: "so when you do your research you get to understand something about mental health" (participant 15). Those that indicated doing research used social media or mental health programmes to gather information. All participants that sought out such education themselves were eager to discuss their own difficult experiences, showing far less self-stigma than those who knew little about the topic.

Sharing with Others

Reaching out for help regarding mental illness can be extremely difficult in Kibera, for fear of loss of belonging (as indicated above). Most participants will reach out to one trusted friend or relative, and some to a select few, with positive effect. Overcoming the fear of sharing does not decrease discretion taken, however: “Some people give you hope, and they help you. But others I cannot tell them, because they cannot help you” (participant 10).

Participants with previous mental illness experience or education indicated being willing to listen to anyone that needs help with mental illness struggles: “When someone tells me he or she has mental illness, I prefer to befriend them… and hear what they are going through” (participant 7) and “when someone tells me they struggle with mental illness, I take it so seriously, because it’s a serious matter” (participant 5). Hearing what others are going through also has positive effects on the individual’s understanding of themselves: “my peers started sharing about their experiences. That's when I also became more open to interrogate my own experience… and started to understand what my, you know, experience has been throughout my life” (participant 14). However, those who had had little to no education about mental illness indicated more difficulty speaking about this topic, and would rather refer those with mental illness to professionals.

Participants who lack community were more likely to indicate suffering from mental illness, and from its stigma. For instance: “So when [I] go out there, and be ‘hitten’ by a car or something, [I] just feels like its ok, because in this life nobody knows [me], nobody cares about [me]” (participant 23). Thus, having community in which to share is important, but it must be combined with education to allow for (self) stigma to be inhibited.

Awareness and Education

The most mentioned intervention method was mental health education, in the form of school curriculum, trainings, or other awareness activities. Participants argued that once people know what mental illness and mental health care are, they are better equipped to help others and understand

struggle. Participant 14 summarizes what the experiences of other participants show: “Once more people know about mental health, they will be better placed to support each other so they can create a system of collective care, which I feel is really the intervention that people in Kibera need.” The importance of education spreads beyond the current generation: “We youths are the future of tomorrow … if we have a child, that child will also struggle. So if I am educated now, maybe the future will be better than today” (participant 26).

Awareness can be created through the existing education system: “Just the way we have science or environmental health in our schools as subjects, good [mental] health should be part of it” (participant 2). Some participants attend schools outside of Kibera and have experienced mental health education in the form of courses or counsellors at their schools (participants 1 and 26).

Another way to create awareness would be to employ existing organisations to create new programmes: “So the best thing is the way you are doing it now. Maybe some people can come, who are not able to go to school. You will have created some knowledge to them. And they will keep it in their mind. And will help others at home” (participant 11).

Discussion

The data shows that a high prevalence of mental illness exists among youth in Kibera, which reflects the findings of other studies on mental illness in Kenya (Kamau et. al., 2017; Mamah et. al., 2013; Mbuthia et. al. 2018; Mbwayo et. al., 2019; Mutiso et. al., 2018; Ndetei et. al., 2022; Ongeri et. al., 2022). Furthermore, the findings support previous research on high rates of mental illness stigma in Kenya (Getanda et. al., 2017; Mamah et. al., 2013; Mbwayo et. al., 2019; Mutiso et. al., 2018; Ndetei et. al., 2016). However, understanding why and how an individual in Kibera develops mental illness stigma, requires an understanding of the context they are part of.

Stakeholder input was consulted to create definitions for these terms to reflect the social-cultural environment of Kibera. The data dictates ‘wellbeing’ as referring to ‘the ability to cope with

and overcome life experiences (including mental illness).' Additionally, the data shows that 'mental healthcare' does not refer only to specialised treatments, but also care from community members.

Macrosystem: Eradicating a Culture of Shame

The data show a pervasive macrosystem of shame around mental illness, with nearly every participant experiencing or witnessing it. This is most notably seen in the stigmatizing language used. Language is part of the macrosystem, it "simultaneously reflects culture and is influenced and shaped by it" (Jiang, 2000, p. 328). The language used by participants reflect the overarching beliefs of shame around mental illness held by Kenyan society (Mamah et. al., 2013).

In Kenya, shame and the stigmatizing language associated with it have been found to be significantly influenced by spiritual beliefs about psychiatric conditions (in some cases referred to as a 'curse') (Mamah et. al., 2013; Mbuthia et. al., 2018; Mutiso et. al., 2018). Using words such as 'mad' and 'diseased' to describe those suffering from mental illness "create an idea that nothing can be done about [the symptoms], and that [they] are dangerous," (Mutiso et. al., 2018, p. 126).

Furthermore, gender-specific shameful language is used, with phrases such as 'be a man,' and 'don't be weak' teaching young boys not to show their emotions. This showcases how language is used to intensify the culture of shame around mental illness among men, reflecting the findings of Mutiso et. al. (2018), who indicate high attitudes of separatism towards mentally ill persons are observed among men, even those who have mental illness themselves.

With macro-level cultural shame imbedded in language, it becomes difficult not to stigmatize, even unintentionally. Kenyan youth in a 2013 study indicated that the word 'mad' was "inappropriately stigmatizing," but since they have only been taught a limited vocabulary, they do not know what else to use (Mamah et. al, 2013, p. 520). Phrases such as 'someone who is not feeling well' when discussing mental illness are indicated to reduce shame. Thus wide-spread basic psychological knowledge is necessary to change the language from one that reflects a culture of shame, to one that promotes wellbeing.

Exosystem: Government and NGO Involvement

Maintenance of Poverty

The data shows that financial stress is indicated to be a main reason for mental illness development, consistent with findings that poverty is a common risk factor amongst those seeking psychological help (Kyeii et. al., 2014; Lingman and Lyden, 2015), and linked to mental health issues and suicidality (Ndetei et. al., 2022). The data further shows that suffering from financial stress is highly stigmatized.

For this factor, it is important to understand the *time* element of the ecological systems theory, which looks at the historical factors that directly influence individual development (Bronfenbrenner, 2005). Kenya was colonized by the British Empire from 1888-1963 (BBC, 2022). Nairobi was created as a city for colonisers, with non-Europeans required to live on the outskirts in "native reserves" (2022) such as Kibera. British colonizers took over vast amounts of land from various tribes, leaving them without wealth. When Kenya gained independence, Kibera became an unauthorised settlement for those who could not afford regular housing and remains so today (*Kibera: Always deprived but rarely depressed,* 2020). A large amount of wealth in Kenya is still held by (foreign) entrepreneurs, expats, government officials, and a select few wealthy tribes, while tribes who lost their land and wealth during colonisation have not been compensated (Greer et. al., 2023).

Thus, the *time* component provides the historical context needed to understand that Kiberan poverty and unemployment exemplify unintentional structural stigma (Corrigen et. al., 2004) as exosystemic actors withhold from providing economic relief that is needed both to reduce financial stress and/or afford mental health care facilities. Additionally, it is important to understand that unintentional stigma often "reflects contemporary social structures that are reinvigorated by past forces that originally represented intentional institutional discrimination" (2004, p. 489). The intentional racial and ethnic discrimination set up by the European colonizers is the historical force that led to Kibera as it exists today, including its mental illness and suicide burden. Mental illness

stigma in Kibera is the aftermath of structural historical and economic discrimination processes, held in place by continued unintentional stigma.

In a society with a macrosystem culture of shame, and an exosystem that does nothing to eradicate poverty, the burden of financial stress has developed into a taboo topic. Participants indicate that suffering has become so normalised in Kibera, that acknowledging the struggle is considered 'weak.' This attitude reflects an understanding that little change in governmental aid can be expected, and thus in order to keep living, "problem-focused coping" is preferred over discussing the difficulties living in Kibera entails (Mbuthia et. al., 2018, p. 10).

Participants who are aware of the stigma around financial stress indicate that introducing safety and security for those living in Kibera would drastically improve wellbeing. Recent studies emphasize this same idea, even indicating it to be "one of the most important contributions local authorities can make […] in particular, investment in providing or upgrading basic infrastructure in slums—such as water and sanitation services, drainage, and roads and pathways—can maximize the use of labour-based methods" (Majale, 2018, p. 272). Such contributions, however, seem far-fetched while the government profits from keeping Kibera poor – a radical systemic change would be required.

Mental Health Education

Kibera currently has no government-endorsed mental health education courses in its schools (Mbwayo et. al., 2019). Participants of this study indicate wanting such programmes, considering them the easiest way to spread awareness. However, the education system, and funding it gets, are not set up to provide such courses in every school (2019), indicating unintentional stigma in the form of economic restrictions (Corrigan et. al., 2004). Kenyan schoolteachers are aware of their students' suffering, but unable to help due to a lack of mental health training and a lack of time in the school programme (Mbwayo et. al., 2019). Implementing mental health education as part of the school system would thus require a large exosystemic change.

However, such change is not impossible. Some participants indicated already having counsellors or 'life skills' classes in their high schools, meaning that this change is already happening. Schools in Kenya have departments of guidance and counselling (2019), these can be mobilised to improve the school community's knowledge on mental health through various methods. Furthermore, Mbwayo et. al. (2019) recommend that teacher trainings include mental healthcare, so that teachers are able to provide appropriate guidance or referral of their students. These methods reflect the interventions participants indicated as being the most successful ways of decreasing stigma in Kiberan society, by providing knowledge and awareness to a large majority of the population.

Changing the education system cannot occur in a vacuum, it must take into account other bioecological systems; these interactions form Bronfenbrenner's concept of *process*. For instance, courses/counsellors could take into account how language perpetuates shame, opting for destigmatizing language instead. Furthermore, understanding the financial stress Kiberan youth experience would help provide adequate knowledge about appropriate mental healthcare.

NGO Programmes

Changing or adding on to the existing educational system should not be the only way to educate about mental illness (stigma). Though most participants mention school as the best place to introduce such education, some mentioned that youth are unable to go to school for various reasons. Existing youth programmes (often run by NGOs) in Kibera can use their platform to educate about mental illness, reaching both those that go and don't go to school[5].

There are certain limitations to creating NGO-run awareness programmes. The main limitation being a lack of such programmes for boys and men, or that when programmes that do

[5] Some NGOs are already trying to create more mental health awareness: Uweza Foundation is already taking large steps in their Golden Girls Programme in which mental health has become a recurring topic. However, they are "strapped with resources, in terms of funding, time, and expertise in mental health" (participant 24), making implementing new or improved programmes a difficult endeavour.

exist for this target group, none show up due to the higher shame seen among males for this topic. Thus, being aware of the existing (gendered) shame culture is important when implementing programmes to improve mental wellbeing.

Mesosystem: Need for a Community of Care

The impact of the abovementioned changes could change how the mesosystem of Kibera functions. The findings show that the current wellbeing of youth is negatively affected when there is a lack of community care, a direct result of stigma on larger societal levels. Collective care here refers to psychological care that does not require specialized treatments, but rather the active communication about mental health issues among schools, parents, peers and the individual youth. Such an approach is the "cornerstone in improving child mental health, particularly in the lack of extensive specialist resources" (Getanda et. al., 2017, p. 206), impacting not only the current generation, but those to come (Atlas, 2023).

Microsystem: (Self) Stigmatizing Behaviour

The most proximal level of society described in the ecological systems theory is the microsystem. In this setting the bioecological concept of *person* is important: the individual's own experiences and cognitions impact their stigma development (Corrigan et. al., 2004). The results of this study are in this aspect similar to those of studies done in other countries (DeLuca, 2020): youth who have (had) mental illness, or cared for someone with mental illness, exhibit less stigmatizing behaviour.

Previous research shows that youth exhibit more (self) stigmatizing behaviour and cognition as they get older (Heary et. al., 2017). The findings from this study indicate that this only holds true in Kibera when there is a lack of mental illness education, and/or community. Education provides an understanding that mental illness can be attributed to more than individual shortcomings, encouraging help seeking behaviour. Additionally, those who have at least with one trusted person

with whom to share the issues they are going through, are creating connections that reduce mental illness severity (Getanda et. al., 2017) and actively fighting against "secrecy and silence [that] perpetuate a cycle of isolation and interpersonal strain" (DeLuca, 2020, p. 162).

A Need for Tailored Interventions

The burden of stigma reduction in Kibera falls predominantly on community, reflecting interventions using social-cognitive models of stigma development which focus on creating positive coping mechanisms and strong interpersonal relationships (Corrigan et. al., 2004; Yang et. al., 2007). Thus, those who do not have a safe community member with whom to share fall victim to (self) stigma and increased mental illness risk. Here, tailored preexisting interventions that strengthen individual and group resilience (see DeLuca, 2020, and Heary et. al., 2017) may be useful to reduce personal risk.

However, the data indicates that it is predominantly exosystemic factors, including intended and unintended structural stigma (Corrigan et. al, 2004), that maintain a low level of wellbeing among those afflicted. There is a greater need for structural economic reform of Kibera, and providing youth mental health education and services that respect sociocultural factors (such as language and gender). Together these are "interventions based on observation of the everyday lives and the actual difficulties that stigmatized individuals face [which] may better address… local stigma experiences" (Yang et. al., 2007, p. 1533).

Limitations

This study presents the data of 27 participants to develop a contextual understanding of how stigma is developed and maintained within Kiberan society. However, only allusions to the inter- and intralevel processes can be made, a key component of the bioecological theory. Thus, this paper should be seen only as an indication of the lived experience of stigma on multiple levels of society, and a resource for data that can be used as stakeholder input for intervention design in Kibera. It provides an overview of both social-cognitive and structural discrimination models of stigma

development, but does not present a complete model of all the bioecological systems influencing stigma development, as this would require a larger study format.

Conclusion

The consequences of mental illness stigma are manifold and can be seen on all levels of Kiberan society. By integrating models of stigma development into a bioecological model of development, a holistic understanding of this stigma is created. The data shows that intentional and unintentional systemic stigma, as well as individual social-cognitive factors have harsh effects on the wellbeing of youth: nearly every participant interviewed in this study has dealt with (severe) mental health difficulties, and has struggled to find care and understanding regarding their experiences.

Currently, there is little being done to eradicate stigma, however, participants indicate various methods to do so. The most feasible manner is utilising a bottom-up approach, in which microsystem interventions such as creating connections between community members, facilitating sharing, and introducing coping strategies to use during difficult experiences are introduced, methods which are indicated to increase the well-being of participants (Corrigan et. al., 2004; DeLuca, 2020). However, this would require knowledge of mental healthcare, and intrinsic motivation to provide care to community members, in all individuals in Kibera. Since that is not the case, interventions on larger systemic levels are imperative.

The participants of this study express a desire for change on an exosystemic level. This demands top-down work, including government involvement in eradicating poverty, and educational reform. Participants also indicate how other stakeholders on this level, including NGOs and other organisations already active in Kibera, have a pivotal role in creating changes that can destigmatize mental illness, which will positively impact the wellbeing and access to care of youth.

The data gathered in this study outline the following recommendations for future research: there is a need for research that explores how organisations with limited resources can effect meaningful exosystemic change, as well as methods to persuade governmental actors of the

importance of allocating resources to this field. In order for stigma, and mental illness, to decrease, Kibera can not rely on microsystem resilience alone. Without larger systemic change, the suicide rate of 11 in 100.000 (World Health Organisation, 2021) will only increase, each suicide a stark reminder the systemic failures that caused it.

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Appendix 1

Semi-structured interview questions:

Please give your definition of “mental illness”

Have you ever struggled with mental illness? If so, please explain in what way:

Do you know anyone that struggles with mental illness? If so, explain in what way, and what is their relation to you?

When did you first learn about “mental illness,” if at all? (at school, due to experience…) Please explain.

What will you do if one of your loved ones struggles with mental illness?

What do you think (or will you think) when someone tells you they have mental illness?

Do you know where and how to get treatment for mental illness – either for yourself or for others?

Do you think it is important to be educated on mental illness while living in Kibera?