Community perceptions and knowledge of mental illness in the rural Kisumu region of Kenya

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Abstract
Objective: The University of British Columbia's Global Health Initiative (GHI) collaborated with the NGO, Kenya Partners in Community Transformation (PCT), to explore community knowledge, beliefs and practices surrounding mental health and illness in the rural Kisumu region.

Methods: Five focus group discussions (FGDs) were held in three rural communities within the Kisumu region. Demographic groups surveyed included: women (n=54), men (n=14), and Community Health Workers (CHWs; n=36). Focus groups probed community mental health knowledge and included case-based vignettes describing presentations of mental illnesses as outlined in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition.

Results: Participants were asked to define mental health, mental illness and barriers to mental health care. For a total of 104 participants (Figure 1). Methods

Conclusion: Overall, FGDs with community members and CHWs indicated education on mental health was limited. Qualitative data gathered will be used to tailor WHO mental health modules to meet the unique needs of CHWs living in the rural Kisumu region of Kenya.

Introduction
Mental illness accounts for approximately 7.4% of global disease burden,1 with depressive disorders projected to be the leading contributor to global disease by 2030.2 This is concerning in Kenya, where limited resources and legislation have resulted in inadequate mental health services.3 The World Health Organization (WHO) reports 0.19 psychiatrists per 100,000 people in Kenya compared to 7.79 and 12.40 in the US and Canada, respectively.4 This scarcity of psychiatric resources results in many individuals consulting traditional healers for mental healthcare, especially in rural regions.5 Disharmony in mental healthcare provision suggests a need for collaboration between traditional healers and the biomedical healthcare system to create an integrated care model.6 Community health workers (CHWs) are volunteers who liaise between healthcare centers and community members to provide education and refer individuals to healthcare services as needed. Thus, they are uniquely positioned to connect community members with necessary mental health services.7

Limited research exists on perceptions of mental health in sub-Saharan Africa, likely secondary to the limited mental health resources in African countries.8 Kenya Partners in Community Transformation (PCT) is an NGO that addresses the needs of three communities in the rural Kisumu region: Kit Mikayi, Kaila, and Kajulu Koker. The University of British Columbia's Global Health Initiative (UBC GHI) has partnered with PCT to develop and implement sustainable community projects. In 2015, PCT identified mental health education as a priority topic within the community. Accordingly, our study used focus group discussions (FGDs) to evaluate knowledge, perceptions, and practices surrounding mental health in the Kisumu region. A FGD is an open forum utilized to elicit themes and overarching attitudes on a topic to gather qualitative data. Although other studies have evaluated mental health in Africa, this study presents novel research specific to the Kisumu region of rural Kenya. Qualitative mental health research has been completed outside of Kenya or in urban populations with different demographics.9,10 It would be unfair to generalize data from other urban, African studies to these rural communities, which have a distinct language and culture. Accordingly, qualitative data collection was necessary to appropriately tailor mental health education materials for local individuals.

The research team hypothesized that community knowledge of mental health would be limited, and that treatment options would be based upon cultural and spiritual beliefs. Although mental health education is not typically incorporated into CHW training, it was hypothesized that, compared to community members, CHWs would have a greater experiential understanding of mental illness and appropriate treatment options because of their unique background.

It is our hope to address potential mental health disparities in the rural Kisumu region by using the qualitative data collected in this study to develop education materials that respond to individual and cultural values and add to the baseline understanding of mental illness in the region. The qualitative results from this study will be used by future GHI teams to tailor WHO mental health modules and develop culturally appropriate workshops for CHWs to increase awareness, improve screening, and educate community members on mental illness. As a precursor to these future efforts, qualitative data collection was considered to be more effective as an initial study methodology rather than the immediate use of quantitative methodology, which may have imposed too narrow a focus.

Methods
The study protocol was approved by the University of British Columbia’s Behavioural Research Ethics Board.

Participants
To survey community knowledge and attitudes of mental health, five FGDs were conducted in Kit Mikayi, Kaila, and Kajulu Koker: one with CHWs (n=36; female = 33, male = 3), one with men (n=14), and three with women (n=54) for a total of 104 participants (Figure 1). Members of all groups, including CHWs, reported no prior training in mental health. PCT staff used network sampling to recruit participants to the study who were eligible according to the inclusion criteria. FGD participants were self-selected to participate, but were screened to ensure location of residence and age between 18 and 50 prior to participation.

Focus group discussions
Community FGDs were divided by gender given the cultural norms of the region, as there was a concern that women may not share ideas in a discussion with male participants. FGDs were held in community centers located in three target communities. Data collection took place from June 18 to July 8, 2015. Consent forms were provided in simple English and Luo, the local language. Consent forms were distributed to all FGD participants and orated in English and Luo. FGDs were audio recorded for future transcription. Participants were given the opportunity to ask questions before consenting. FGDs were conducted over 60-90 minutes, with two facilitators and two PCT translators for each session. Discussion topics were designed to assess understanding of mental health, mental illness, and barriers to mental healthcare. Discussion commenced by asking participants to define mental health and illness. Following this, WHO and National Institute of Mental Health (NIMH) definitions of mental health and illness were shared with participants. Subsequently, case-based vignettes describing mental illnesses, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM–5), were presented, and questions about the patient's diagnosis, function, and quality of life were discussed.11 These vignettes were adapted from DSM–5 Made Easy: The Clinician’s Guide to Diagnosis12 and modified with PCT staff to be representative of life in rural Kenya. The following is the vignette for major depressive disorder:

George is a 40-year-old farmer in your community that has stopped taking care of his land, something he enjoyed a few months earlier. He says he

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feels that the amount of work is overwhelming. He feels constantly tired and is not able to sleep through the night because he worries about his land and feels guilty for not working harder. He has lost his appetite and appears to be losing weight.

FGD questions explored treatment options and barriers to care. The full FGD script template can be seen in Table 1. After the FGD, attendees were provided with food and travel compensation of 200 KES (approximately $2 CAD) to cover transportation.

Analysis
Following data collection, audio recorded FGDs were translated and transcribed from Luo into English by a private translator from Maseno University. The translator signed a confidentiality agreement to maintain the anonymity of participants. Respondent names were not on the audio recordings. English transcriptions were analyzed independently by four of the authors who had conducted the FGDs. The definitions of mental health and illness vocalized during FGDS were compared and categorized based on WHO and NIMH definitions. Analysis included identifying salient themes and categorizing quotes from discussions into these different themes. Thematic analyses were then combined and verified for agreement between the authors. Participants also responded to one survey question by a show of hands, recorded by researchers.

Results
The data presented are drawn from FGD transcriptions and researcher notes. Mental health and illness definitions Themes extracted from the WHO definition of mental health and NIMH definition of mental illness were used to categorize the FGD qualitative data. The WHO (2014) defines mental health as “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community.” All FGD respondents had a good understanding of mental health and provided responses that fell in line with identified themes, as listed in Table 2. The NIMH (1999) defines mental illness as “health conditions that are characterized by alterations in thinking, mood, behavior (or some combination thereof) associated with distress and/or impaired functioning.” Overall, participant responses appropriately described mental illness; however, some responses did not fall in line with the definition’s themes and have been reported in Table 3. For example, some participants felt that mentally ill individuals are ‘unclean’, ‘dirty’, and of low socioeconomic status. In Kit Mikayi, four out of seven women’s responses fell outside of the realm of the definition and reflected stigmatizing concepts of psychiatric disorders. In Kaila, there were two out of seven responses in this category. This result was consistent among CHWs, with three out of seven responses similarly defining mental illness with negative connotations. All responses provided in the Kajulu Koker women’s and men’s FGD aligned with the NIMH definition of mental illness. Major depressive Disorder FGDs discussed ‘George,’ presented in the depression case–based vignette. When participants were asked what might have caused George to become like this, three of five responses in the men’s FGD suggested poor nutrition and reduced strength. Two of four responses in the CHW FGD and six out of thirteen responses in the women’s FGDS suggested illness generally as a cause, with only one person from Kit Mikayi stating, “I think George may be... depressed.” One response in the CHW FGD, three in the women’s FGDS, and one in the men’s FGD assessed George’s emotional state: “George has been working hard and had a goal to achieve but seemingly he is disappointed for not getting his desires, so he lost hope and is stressed.” None of the community members suggested a supernatural cause of George’s presentation; however, one CHW suggested George “is bewitched.” Participants were then asked whether George could live a normal life and who could help him. Women from each community stated prayers would help George, whereas CHWs suggested “he can be taken to a faith healer.” Participants in all FGDS suggested hospital referral, including, “George could go to the hospital and get help from healthcare providers,” stated by a woman in Kit Mikayi, and that he “should be taken to the hospital for diagnosis and treated properly,” suggested by a CHW. Many stated counseling would be beneficial, with one man stating, “through counseling, he is able to open up and get proper help” and another Kit Mikayi woman suggesting, “Community Health Workers can also counsel.” A CHW also noted that George could live a normal life “if [he] is counseled,” but CHWs did not suggest themselves as a resource. Access to mental health care was quantified in subsequent discussion. Access to Mental Healthcare Community members identified an array of medical, cultural, and spiritual resources that they would access for mental illness, which are listed in Table 4. During the FGD, participants were asked to respond to the question “Where would you first seek help for mental illness?” The survey results are included in Figure 2. Interestingly, the majority of Kit Mikayi, Kajulu Koker, and the CHW participants said they would go to a hospital; however, community members were more likely than CHWs to access spiritual and cultural resources for primary mental healthcare, or to seek help from friends and family. In fact, when 17 women in the Kaila FGD were surveyed on their first point of care for mental illness, 53% of respondents said they would go to a faith healer, whereas 47% said they would go to a hospital. All CHWs reported they had not received formal mental health training and, therefore, did not self-identify as a resource.

Identified Barriers Barriers to accessing mental health care were discussed in community FGDS. Shared themes included stigma, personal hesitancy, financial barriers, lack of knowledge and support, and distance to access tertiary hospitals. All participants identified finance as a prominent barrier: “treatment is very expensive both at hospitals and even with traditional healers” (Male FGD). A woman in Kit Mikayi noted, “distance to health facilities” and “stigma can make one avoid help.” A woman in Kajulu Koker suggested community “lack of awareness” and another noted, “culture, [as] some people have a belief that hereditary problems must not be taken to the hospital.” A male participant stated: “this is a delicate and sensitive matter, in the society very few are able to talk about it.” Another noted, “most people with the problem or with family members with the
Community members were asked what could mitigate barriers, to which respondents suggested community members increase awareness, promote openness, and reduce stigma. One woman in Kaila noted “we should stop being fearful and stigmatized, and always be outspoken to share our problems to others.” A Kaila FGD participant suggested, “trainings should be organized to create awareness on such kind of illnesses.” Given distance barriers, a woman from Kit Mikayi noted, “we can seek help from [CHWs] to reach those who we are not able to face.”

Discussion

The voiced definitions of mental illness from FGDs suggested many participants held negative perceptions of individuals with psychiatric disorders. From all the women’s FGDs, 35% of responses on mental illness fell outside of the NIMH definition themes and reflected stigmatizing concepts of psychiatric disorders. This result was consistent among CHWs with three out of seven responses similarly defining mental illness with negative connotations, and was in fact proportionately greater compared to all the responses in the women’s FGDs (Table 3). This was a surprising result given the role of CHWs as a health care resource, and may be reflective of negative experiences working with mentally ill patients while lacking the expertise to effectively manage these cases.

Based on the vignette results, only one individual used “depressed” to describe George. Beyond this, no other mental health–related terminology was applied, including among CHWs. This lack of knowledge on psychiatric conditions and terminology may hinder CHWs’s ability to screen for psychiatric morbidity in the community and provide appropriate treatment.15 Given the negative views toward mental illness expressed by some CHWs, it is necessary to address this gap in knowledge.

FGD participants consistently highlighted stigma and a lack of community support as barriers to care. Furthermore, as reflected in Table 4, cultural and mythical perceptions of mental illness often factored into treatment choice, with many seeking help from faith healers; this may have had the effect of delaying or replacing treatment at local clinics offering access to medications and counseling from trained nurses. Interestingly, no participants indicated they would first seek help from a psychiatrist for a mental illness. This reinforces the importance of understanding the local community’s educational needs and current understanding of mental illness to create culturally appropriate interventions.

This is the first study evaluating mental health in rural Kisumu, with no existing local data. Data gathered from FGDs will be used to clarify misconceptions, increase awareness of mental health topics, and provide education on appropriate treatment choices, which may be used in conjunction with traditional spiritual consultants. Given that CHWs serve as community health care informants, supporting them would have a significant impact on furthering community education. Data will be used by future GHI teams to inform the development of culturally appropriate mental health modules to provide basic mental health training to CHWs.16

The small sample size used in this study provides a preliminary understanding of attitudes and perceptions in the area, and future studies may use larger sample sizes to improve the generalizability of these results.

The participants of this study self–selected to engage in the FGDs, and therefore, the results are susceptible to selection bias. However, there was a diverse range of study participants varying in age, and FGDs targeted all populations including men, women, and CHWs. CHWs from all three communities attended their FGD.

FGDs were conducted in English and translated by PCT workers into Luo, risking mistranslation or loss of meaning. To mitigate this, FGDs were audio recorded and sent to a translating service to transcribe Luo responses into English prior to analysis.

Given that a qualitative study design was implemented that required subjective interpretation of discussion points to extrapolate themes, observer bias may have influenced conclusions. To mitigate observer bias, team
The data from focus group discussions have been analyzed in context of four themes used to describe an individual from the NIMH definition of mental illness, including someone who has altered thinking, altered behaviour, impaired functioning, and is distressed. An additional section was added for responses that did not fit these definitions.

Table 3 | All participant responses to discussion question: “In your own words, how would you define mental illness?”

The data presented includes suggestions provided by the men and women’s focus group participants. The table includes suggestions provided by the men and women’s focus group participants.

Table 4 | Suggested resources for mental illness from focus group participants

The table includes suggestions provided by the men and women’s focus group participants.

**Conclusion**

As the global disease burden of mental illness continues to grow, appropriate mental health interventions become increasingly important. Study results aligned with the hypothesis that knowledge of mental health is limited in the rural Kisumu region among community members. Unsurprisingly, community members and CHWs suggested treatment resources that incorporated cultural and spiritual practices. Unexpectedly, CHWs held many negative perceptions of mental illness.

Although there were numerous barriers to accessing mental health services, community members identified potential solutions, including increased openness in the community and training programs for education that will reduce stigma and improve awareness. CHWs are in a unique position to provide education to community members, but currently have received no formal training in mental health. The results of this study will be used by future GHI teams to modify WHO CHW Mental Health Modules to meet the specific cultural needs of the rural Kisumu communities. The research team hopes this will empower CHWs to become an important community resource for mental health information.

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**References**