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Individual and community experiences and the use of language in understanding diabetes and depression in rural Kenya

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ABSTRACT

As the prevalence of long-term conditions continues to rise it becomes increasingly important to identify ways to mitigate their effects, including the psychological impact. In rural Kenya identifying people with diabetes or mental health problems is challenging due to the stigma and negative experiences within community settings.

Four broad themes were identified; (1) misconceptions and stigma: the use of language, (2) treatment and medications, (3) community beliefs and alternative treatment pathways, (4) the role of informal and formal care.

Our study demonstrated the detrimental effect of the use of stigmatising language and misconceptions surrounding diabetes and depression at both the individual and community levels. Inequalities in health care access were observed and a lack of resources in rural communities was evident. Improvements in support for health care workers at the community level as well as acknowledging the importance of informal care could help improve the psychological and emotional impact of diabetes and depression.

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Diabetes; depression; rural Kenya; community health workers

Introduction

As people live longer and life-styles change, the prevalence of long-term conditions such as diabetes is rapidly increasing with the International Diabetes Federation (International Diabetes Federation Atlas, 2019) estimating that 1 in 10 people currently have diabetes worldwide (International Diabetes Federation Atlas, 2019). Africa has the highest proportion of deaths in people with diabetes over the age of 60, and by 2045 the number of people with diabetes in this region is expected to increase by 143% from 19 million in 2019 to 37 million (International Diabetes Federation Atlas, 2019). In addition to the impact on mortality, a number of both physical and mental co-morbidities are associated with diabetes such as cardiovascular disease and renal failure, and co-morbid mental disorders, all of which are becoming widespread (Lund et al., 2012; Mutiso et al., 2018; Shirey et al., 2015). These conditions have a significant economic impact, put a strain on existing health systems and lead to poor quality of life (Akena et al., 2015; Moussavi et al., 2007).

Evidence has shown that people with diabetes are significantly more likely than those without diabetes to have co-morbid depression or other mental health problems which may have a

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detrimental effect on diabetes self-management and overall quality of life (Moussavi et al., 2007; Van der Feltz et al., 2010). In Kenya, up to 60% of people with chronic physical diseases (including diabetes) may have clinically significant levels of depressive symptoms, although they are rarely diagnosed and cared for (Lloyd et al., 2018a; Lund et al., 2012; Ndetei et al., 2009). However, prevalence estimates differ according to setting (rural vs urban; community vs secondary care provision), as well as gender and socio-cultural norms (Mendenhall et al., 2017; Musyimi et al., 2017; Mutiso et al., 2017). In addition, it is often difficult to quantify prevalence due to a reluctance to report mental health problems as a result of the stigma and cultural norms surrounding disclosing a mental health problem. Lack of knowledge and understanding of the local language and expressions used to describe mental or physical health problems which are culture-dependent and often distinct from global definitions of mental distress or low mood significantly contribute to this problem (Mendenhall et al., 2019; Mutiso et al., 2017). Mendenhall et al. (2019) have reported idioms such as ‘thinking too much’ arising organically to describe depression which challenge the western biomedical model of mental illness.

Negative stereotyping of the behaviour of individuals with mental illness along with self-stigma may lead to low rates of reporting, social isolation, and a lack of a sense of belonging which can exacerbate symptoms as well as lead to the absence of support and care (Mutiso et al., 2017). Attitudes towards mental illness are often operationalised through language and the use of negative, judgemental words or phrases or behaviour towards those identified as having mental health problems, reinforcing a sense of separation from their community. Moasun and Mfoafo-M’Carthy (2020) note that proverbs, which are commonly used in some African countries, often contain negative connotations which have the power to harm individuals through stigmatisation, particularly those with long-term conditions, and contributes to their risk of marginalisation and social exclusion.

Reported rates of mental illness also depend on the method of identification, the language used and the availability of treatment and care (Lloyd et al., 2015; Ndetei et al., 2009). Although the World Health Organisation (WHO, 2010) recommends the adoption of the mental health Global Action Programme Intervention Guide (mhGAP-IG), mental health screening is not given priority especially given scarce resources and lack of local expertise. This has been significantly exacerbated during the current COVID-19 pandemic (Cénat et al., 2021; Kar et al., 2020). In rural Kenya, where our study was carried out, this complexity places a significant burden on the work of the Community Health Workers (CHW) who play a vital role in the identification and referral of people with co-morbid diabetes and depression. As our work in one community in rural Kenya progresses and addresses the negative perceptions held and the language used by its members, it is hoped that individuals will feel more empowered to come forward and report mental illness so that they may access treatment and support.

Materials and methods

This study was carried out under the auspices of the Community Intervention Network for Diabetes and Depression (CoIN-DD) research group. The CoIN-DD network, funded by a Global Challenges in Research Networking grant, was a collaboration between researchers in the UK, Kenya, Uganda, Ethiopia, and Tanzania which aimed to build capacity in researching co-morbid diabetes and depression. A series of events took place between the investigators which included sharing research skills and expertise with early career researchers and examining the experiences and understanding of diabetes and depression from the perspective of a range of stakeholders.

In order to advance this work, a phenomenological approach was taken, that described the lived experience of the individual within the context of their environments. Qualitative methods were used in order to gain an in-depth understanding of the needs of rural communities from the perspectives of individuals with diabetes and depression along with a range of health care workers. The

objective was to draw on the findings of this research in order to develop educational materials addressing the stigma surrounding diabetes and depression. Both individual interviews and focus groups were conducted as effective ways to increase understanding of service provision needs to assist in the development of subsequent intervention programmes (Halcomb et al., 2007).

Study site

Semi-structured interviews were conducted in the board room of the local hospital in Makueni County, a rural area with high rates of undiagnosed diabetes and depression situated in the lowlands of southeastern Kenya. It performs poorly in most socio-economic indicators and relies on climate-dependent agriculture. Individuals were recruited to the study by the diabetes clinic doctor at the participating hospital which was selected due to the presence of a psychologist for accurate identification of people with depression.

Study participants

Between September and October 2019, a purposive sample of health care providers (Health Care Workers: HCW; Community Health Workers: CHW; Care Givers: CG; Public Health Officer: PHO) and people with co-morbid diabetes and depression were recruited using hospital records to identify the most recent and available participants. Where necessary a diagnosis of depression was confirmed by the hospital psychologist after receiving a referral from the doctor at the diabetes clinic in the same hospital. HCW were recruited from the participating hospital, with priority given to those working in the diabetes clinic and those on duty on the day of the interviews. CHW were selected based on active participation in monthly community activities and meetings led by the PHO.

Data collection

Audio recorded semi-structured interviews lasting between 19 and 110 min were conducted in the preferred language (English or Kikamba) by a research assistant (RA) and one of the authors (CM) who was a community mental health researcher, both of whom being bilingual.

A total of six focus group discussions (6-8 participants per group) and 10 key informant confidential interviews were conducted. The latter were carried out with three people with diabetes (PW DM; age range 43–72 years) and three people with both diabetes and depression (PW DM&DEP; age range 18–79 years) who were attending the local hospital for diabetes care and three community leaders (two local chiefs and one opinion leader) and one PHO. Focus group discussions took place with two groups of HCW (age range 27–58 years), two groups of CHW (age range 35–77 years), and two groups of CG (age range 28–62 years) who were either spouses or relatives of the participants with diabetes and/or depression. HCW are qualified clinicians including nurses and clinical officers, whereas CHW are not qualified but receive a short training to provide basic health care within the community including hand-washing, diabetes screening and referral. They have a significant influence within the communities in which they serve.

Ethical approval was obtained from Maseno University Ethics Review Committee in Kenya. One of the authors (CM) with experience in conducting qualitative interviews explained the study and all participants provided written informed consent prior to participating.

Data analysis

The interviews were transcribed verbatim by the research assistant (RA) and those conducted in the local language (Kikamba) were translated into English. Where necessary a discussion of any translation/interpretation issues took place between one of the authors (CM) and the RA. The data were

exported into NVivo software (version 12) by the RA using a codebook to identify initial themes. In order to familiarise themselves with the data two authors (CL, CM) read the scripts independently (one being a native speaker of Kikamba). An inductive approach was taken and in-depth discussions took place with the RA in order to identify emergent themes and sub-themes (Braun & Clarke, 2006). Subsequent discussions occurred to obtain a consensus on the final themes as discussed below.

Results

Four themes were identified by the researchers: misconceptions and stigma and the use of language, treatment and medications, community beliefs and alternative treatment pathways, and the role of informal and formal care. Stigmatising language was apparent and impacted on the experiences of those with diabetes and depression, often leading to the concealment of these conditions. This non-disclosure in addition to the prohibitive cost of medications had implications for treatment and care. Family members were vital supporters of people with diabetes and depression, however, conflicting feelings of becoming a burden whilst needing to rely on them were apparent. CHW were trusted members of their community and provided an important conduit between informal and formal care.

Misconceptions and stigma; the use of language

Study participants portrayed a range of misconceptions about both diabetes and depression and the causes and possible symptoms, as evidenced by the language used which suggested a lack of knowledge and understanding of these conditions. Depression was commonly described using stigmatising words or phrases such as people having a ‘bad brain’, being a ‘mad person’, ‘uncouth’ or ‘arrogant’ (see Table 1). Stigma was felt not only by the person with these conditions but also by family members and often led to isolation from their community. A participant with both diabetes and depression described their experience of ‘gossip’ in the community and the use of the word ‘zombie’ to describe people with depression. The idea of the brain being damaged or not working properly and the negative reactions of others was commonly described, for example ‘You see and hear people point and say, ‘is your brain not functioning properly?’ (PW DM&DEP), or ‘mental illness damages peoples’ brains’ (PW DM).

Depression was frequently described in stigmatising language:

someone who presents with, like, some funny characteristics like talking on your own along the roads or going around collecting what we call rugs; you are uncouth, you are unkempt (HCW)

Table 1. The language used to describe diabetes and depression.

Diabetes	Depression
Sugar disease ‘I am a bee’	Mena akili nthuku (they have a bad brain)
Expensive disease	Ena meesilya maingi (stressful thoughts)
Kisukari (big sugar disease)	Nduuka (madness)
Mtu was sukali (someone with bad sugar disease)	Kulekya isaa (someone who has lost touch with the world)
Muundu wa sukali (a person of sugar)	Muundu wa nduuka (a mad person)
Usu awaie muyu (that one is sick of sweetness)	Mena ngulu, ena ngulundekwenda kuya (uncouth, arrogant)
Uwau utavoawa (disease that cannot be treated)	Andu ala mathokoekaa mutwe (those with a disturbed mind)
Wiwa group isu (you belong to that group)	Uwau wa muvusavusano (confusion disease)
Very dangerous	Thing’ai (like a zombie, dementia)
A terminal illness	Muundu wa mbulwa we ee ni wa thing’ai (a very forgetful person is like a person suffering from dementia disease)
Contagious	Akili niyo ithamaa (the brain moves elsewhere)
General body weakness	The person’s brain is not content, his/her thoughts are not good

It was acknowledged by many of the study participants that depression was often hidden due to the stigma surrounding the condition and it was not to be discussed openly because it was perceived to be 'foolishness' and would be met with mockery:

they (people with depression) don't freely talk about their depression ... it's perceived to be associated with foolishness (PW DM&DEP). All they (the community) do is mock people suffering from diabetes and/ or depression. (PW DM&DEP). As the PHO stated:

People will not even talk about depression ... very little is known ... it's not taken heavily like other conditions. (PHO)

Symptoms of depression were often described in terms that were rooted in the social, behavioural and cultural context of the everyday lives of people living in this rural community but could sometimes be seen to be aligned with some of the symptoms of depression measured in western settings. For example, HCW described possible symptoms as feeling intolerant of others, not wanting to interact with people or having little interest in doing things. Other descriptions included 'not taking a bath' and 'not doing delegated duties'. Cognitive symptoms of depression were expressed as 'stressful thoughts', 'the brain becomes mixed up', 'his thoughts are not good', and 'the brain is not content'. Although not identified as such by the participants, the symptoms of depression were often blurred with those more commonly associated with dementia such as forgetfulness and finding it difficult to communicate.

Participants described diabetes in a number of ways and although some of the symptoms were accurately identified by the HCW, the language used in many other instances demonstrated a lack of understanding of the condition, for example describing diabetes as a 'disease that cannot be treated' or it being 'contagious'. The language used often had negative connotations for example it was described as 'a shameful disease'. The quote below illustrates the high degree of negativity towards diabetes that was experienced by the participants:

people prefer to suffer from AIDS than to suffer from diabetes. The community talks very negatively about the diabetes disease, they consider it a very contagious and bad disease. (P with DM)

Experiencing problems with their diabetes, for example when glycaemic control was poor, was sometimes portrayed as being caused by demons or witchcraft:

In many cases, people that visit traditional herbalists or witchdoctors think whenever their health status deteriorates, somebody has bewitched them, a neighbour has cast demons on them. (P with DM)

These perceptions, emanating from members of the community, often exacerbated individuals' feelings of culpability for having diabetes. As one participant said, it was as if 'you went looking for the disease'. In some instances, self-blame was observed more in men than women, citing their previous 'reckless' lifestyle, lack of exercise and drinking alcohol. Indeed, blame for diabetes was often placed squarely at the feet of the individual with the condition by members of their community:

Yes they do blame me for causing my diabetes disease' (P with DM and DEP).

... (for the men) they say it is because of their past life They never did exercise, they lived a reckless life in terms of diet and lifestyle. They blame themselves for the lives they lived, but for the women (it) is like a curse (PHO)

There appeared to be far stronger negative opinions concerning mental health compared to diabetes, albeit that blame was more apportioned to people with the latter. This was reflected not only in the language used to describe depression as discussed above, but also in ideas about what the appropriate care for someone with depression might be. Whilst the participants agreed that people with mental illness should be supported, they cited examples of individuals having their movements severely restricted by their families, for example not being allowed to leave their compound or, in one case, being locked in a room. In contrast to identifying people with diabetes, HCW did not have access to any guidelines or a clear referral process for the treatment of depression.

A blurred boundary or overlap between diabetes and depression was demonstrated by many of the study participants. Being depressed was sometimes blamed on having diabetes and feeling guilty about being diagnosed with the latter condition and this was acknowledged by the HCW as well as the CG as something to be aware of:

It's therefore important that the person taking care of a person suffering from diabetes understands the psychological emotions and when they find the person's tempers rising they should work to ensure their tempers stabilise so that sugar levels don't go up. (CG)

When a person suffers from diabetes there are so many things they don't feel interested in doing, neither do they appreciate the joy of living. (P with DM)

Despite some increasing awareness, erroneous beliefs about diabetes and depression remained. To counteract this, the PHO stated that there needed to be more education to increase understanding in the community and reduce stigma. One solution offered was to support those who were aware of depression and diabetes (whether or not they had been diagnosed with either of these conditions) to disseminate information to the community in a style that would address common myths and beliefs and encourage identification and treatment.

Treatment and medications

Taking up diabetes medications once diagnosed did not appear to be straightforward; not only was the cost of drugs a major barrier but not wishing to disclose their diagnosis also meant that prescriptions were not always filled. The PHO described one instance where non-disclosure of the diagnosis had led to dire consequences. In her view, felt stigma had led to the person not filling her prescription, falling seriously ill and requiring urgent medical care. One particular reason for non-disclosure was evident in other women's descriptions of their fear that having diabetes would impact on their chances of marriage, their sexual activities and becoming pregnant.

Despite the existence of an innovative health insurance programme in the county, the costs of treatment for diabetes when referred to care facilities outside the county were often not covered by the scheme and so remained a significant barrier to receiving care. The nearest hospital provided free care if the individual had health insurance, however the cost of transport to that facility often prohibited them from accessing treatment. Problematic access to health care services was highlighted by the PHO, who described a shortage of drugs, the cost of getting to the hospital and the long queues on arrival. Access to medications was often impossible due to the lack of availability of drugs at hospital clinics and a compromise on where and what was obtained had to be considered.

You can imagine someone writing for you a drug prescription and they don't know if you even have the money in the first place! (P with DM and DEP)

Recently I bought only one type of medicine; I didn't have enough money. I had to make telephone calls to ask where I could get the medicines from and send someone to go buy them for me. (P with DM and DEP)

Non-disclosure, lack of access to formal medical care as well as felt stigma often led to the seeking of care and support from other avenues and was influenced by the beliefs and attitudes of the wider community in which individuals lived, as discussed in the next section.

Community beliefs and alternative treatment pathways

Screening for diabetes takes place at the community level in rural Kenya. However, despite diabetes becoming more common, as discussed earlier not all individuals with this condition felt able to disclose their illness to others in their community. They preferred to remain socially isolated, deciding not to attend public events such as the baraza (a community gathering usually organised by the local chief) which are an integral part of rural society.

... some of these conditions, especially the mental conditions and the long-term or rather chronic diseases, come with a lot of stigmatisation from the society and the community. (HCW)

Social separation and a lack of understanding from the local community was often experienced with the expectation that ‘... a person suffering from depression is not allowed to freely interact with other people in the community’ (P with DM). This resulted in an absence of community support to the detriment of the person with diabetes:

when one is not familiar with them (person with diabetes) at a community function they might think they are simply showing off... people perceive them to be treating themselves as special people. (P with DM)

When I don’t eat their food, they start talking negatively about me. I thus stopped attending the community meetings. (P with DM and DEP)

In contrast some community leaders, afforded a high level of respect, promoted a different perspective on diabetes and depression. The local Pastor was a prime example of this since he had been diagnosed with diabetes. Indeed, two study participants had purposely joined the church where they could freely interact with and felt supported by other members and could receive spiritual guidance. Both informal and formal CG also recognised the importance of the church in the lives of people with diabetes.

... We could freely interact and share with each other openly including giving testimonies. Yes, I feel so honoured when I go in front of the church and am prayed for. (P with DM and DEP)

... what I know about faith in this place is that you get drugs from the hospital that is treatment, then you also see the Pastor for spiritual nourishment’ (PHO).

‘It’s very common to hear (people with diabetes) go for prayers and are prayed for. (CG)

One participant described how at public meetings the Pastor was given food as soon as possible because of his diabetes:

... the community is usually quick to say, ‘Pastor needs to eat now’. ‘Even at church they know immediately the service is over, ugali [a staple food in Kenya] should be cooking’. (P with DM and DEP)

In spite of the work by the local CHW which aimed to de-stigmatise and encourage individuals to come forward to check if they had diabetes, local herbalists and witchdoctors were frequently turned to for help. They were often seen as viable alternatives to hospital treatment, not only because they were more accessible compared to a hospital clinic (which was often many miles away) but they provided an alternative explanation as to why diabetes had been diagnosed and, for some, provided a possibility for alleviating symptoms in what might be a more cost-effective way.

Herbalists and witchdoctors are an integral part of rural society in Kenya and are considered by many as the most appropriate person to approach for help. There was a common perception that somebody had ‘bewitched’ them, or a neighbour had ‘cast demons on them’ so that seeking the help of a witchdoctor was a sensible thing to do. On the other hand, others took the view that seeking the help of herbalists or other traditional healers was not useful and people should only rely on blood sugar testing to determine whether or not someone had diabetes. Indeed, one interviewee who had diabetes said of a witchdoctor that they were fraudulent in their treatment:

... no medical examinations are carried out on the person but instead some marks are cut ... by the witchdoctor and by so doing claims to have administered treatment on the patient. (P with DM)

The role of informal and formal care

There was a clear role for the informal carers of people with diabetes which was embedded in their daily lives. The family frequently provided a safe environment within which care could take place in the face of the often negative views of diabetes and depression in their local community. In

particular, their activities centred on providing appropriate food for their loved ones such as during family events or public meetings. However, this engendered feelings of guilt on the part of the person with these conditions and a fear of becoming a burden on their family:

They must burden themselves to cook the right food for me. This is because if they don't cook the right food for me I will fall sick. Therefore, they feel guilty and I too feel I have offended them by not eating what is available and I choose to rather go without food. (P with DM)

In contrast it was evident that, as observed by one HCW, individuals did not always disclose their diagnosis to family members leading to a lack of support where it was required. In line with the observation made by the PHO, a number of informal CG described frightening situations where the person with diabetes had very low blood sugar and required immediate hospital treatment, which had sometimes been exacerbated when symptoms had been hidden prior to this. Knowledge of diabetes and the need to self-manage the condition was often poor prior to diagnosis, however informal CG reported taking an active role in this regard once the diagnosis was made. Emotional support was offered, although it was often a challenge; one spouse spoke of her attempts to support her husband with his diabetes even though she failed to understand what was bothering him.

The CHW appeared to be a vital conduit between formal (HCW) and informal (family) CG. CHW were embedded within their communities, often relatives or coming from the same households. As one CHW stated '... a great number, a great percentage of community members have benefitted from us'. They were provided with training by HCW which included the screening and referral of people with diabetes and demonstrated a clear understanding of the symptoms of diabetes, confirmation of diagnosis, and recommendations for management. At the time of data collection, however, only five CHW had been fully trained in the area where the study took place. HCW expected CHW to be able to provide psychosocial support for those diagnosed with diabetes and there was an understanding of the need for reassurance to reduce anxieties about diabetes and to look out for signs of depression. If anxieties persisted HCW could refer individuals to the hospital psychologist ('we have one psychologist around'). The term 'psychosocial support' was used by the HCW and defined as encouraging the family to support the person with diabetes in their diet and medication taking. It appeared to be ongoing throughout the experience of diabetes and included providing explanations for the diagnosis and treatment. In some instances, the same health care actions were described as counselling (although there were no guidelines available) by the CHW who reported that they could identify mental illness by observation of behaviour or 'simply by looking at them'. A number of the CHW were clear that their role was to

... explain to them about their diseases because diabetes and depression are not caused by witchcraft, neither are they caused by the abuse of drug substances or anything of the sort. (CHW)

CHW were in an ideal position to dispel these myths as they had been recruited precisely because they were accepted and trusted by members of their local community. Community leaders were also in a key position to relay information and described the importance of speaking the local language rather than English in order to promote greater knowledge and awareness.

In addition to there being only one psychologist available other local medical personnel were scarce and sometimes non-existent, thus those with a potential diagnosis of diabetes were referred initially to a local dispensary and then on to secondary care facilities. As the PHO said:

We only have one nurse. We don't have clinicians, we don't have medical officers of health, so the nurse will maybe diagnose; they find (out) if these people are diabetic and then maybe they give first aid and then refer them for close monitoring and maybe effective treatment at the hospitals. (PHO)

This lack of resources was also recognised by one of the participants with diabetes:

We don't have medics with good skills to handle people suffering from diabetes disease in our community. We heal by chance!. (P with DM)

An awareness of the need for referral when diabetes complications were indicated was evident in the HCW focus group discussions, with a clear role for them in terms of diabetes diagnosis, first treatment, education, and follow-up. However, language such as the terms ‘adherence’ and ‘compliance’ were commonly used, which suggested an ongoing unequal relationship between health care worker and person with diabetes, something which has been observed in other health care settings.

Discussion

This study, in a rural community in Kenya, has demonstrated the negative impact that misconceptions and stigma surrounding both diabetes and depression along with the language used can have on the experiences of people with these conditions. These findings resonate with those in other countries (Lloyd et al., 2018b). Not only did the use of stigmatising language occur in participants with diabetes or depression it was also obvious in the language used by CHW in the focus group discussions. Negative conceptions of the causes and behaviours related to these conditions appeared to be embedded in the cultural and societal milieu within which individuals lived, demonstrated not only by the participants’ choice of language but in their descriptions of their lived experiences. This has significant implications for practice with individuals often feeling unable to acknowledge their condition, resulting in limited access to the treatment and care they required albeit in the current context of scarce resources. Although the WHO guidance on identifying mental disorders (the Mental Health Gap Action Programme – mhGAP-IG which was developed for low-to-middle income countries; 2010) has been adapted for use in Makueni County this reluctance to disclose their diabetes or mental health status remains to be overcome. Community leaders aimed to promote a more supportive arena through public meetings for disclosing a diagnosis of diabetes although this was less evident for dispelling the myths around mental illness. However, in the county where this research took place it has been shown that, once greater awareness has been gained, it is feasible to implement an identification and referral service at the local level (Mutiso et al., 2019).

There appeared to be an overlap between symptoms of depression and dementia as well as distress, feelings of guilt and anxiety related to diabetes which may be difficult to untangle supporting previous research (Snoek et al., 2015). Mendenhall et al. (2019) identified terms with which distress was expressed including ‘stress or agony’ and ‘thinking too much’. She has proposed a model of the ethnopsychology of idioms to understand the experience of distress which considers the socio-cultural context within which people live (Mendenhall et al., 2019). We rarely observed the use of similar terms, rather our participants used more stigmatising language which described behaviours as well as cognitions. One reason for this may be the different populations within which we were conducting our research, with ours taking place in a more rural community. Recognition and acceptance of the local context-specific use of idioms (which often occur alongside biomedical or western terms to describe depression) can improve training and the identification of those in need of care (Backe et al., 2021; Green & Colucci, 2020).

Of note is the weight given to alternative modes of care and a reliance on the religious world for care and support. Bosire suggests this is due to a mistrust of medical care which leads them to seek help from alternative providers and a preference for religious practices (Bosire et al., 2021).

Although the WHO has recommended re-directing funding to community based services, they recently reported that only 18% of all programmes for mental health prevention and promotion were described as incorporating mental health awareness and anti-stigma, with overall levels of public expenditure remaining consistently low along with poor quality of collaborative services (WHO Atlas, 2020). The WHO strategy recommended the identification of appropriate personnel to deliver the programme at all levels of provision although this may vary according to different settings. Green argues that strategies to improve mental health have been hampered by a biomedical approach which has not incorporated expertise at the local level (Green & Colucci, 2020).

In some community settings the provision of counselling by CHW has been observed to help alleviate symptoms of distress with the proviso of receiving appropriate training and support

(Kagee & Le Roux, 2009; Myers et al., 2019). Akena et al. (2020) have identified the potential of peer support as an acceptable way to deliver psychosocial support particularly within settings where resources are scarce. In our study in Makueni County, psychosocial support consisted of CHW providing advice on diet and medication taking, along with attempting to reassure the individual and their family. This is in line with the WHO recommendations which include psychoeducation, reducing stress and strengthening social supports. Only informal support could be provided even though this was central to well-being particularly at the time of diabetes diagnosis. Although the WHO has recommended that Cognitive Behavioural Therapy can be delivered by trained specialist health care workers, this requires redirection of already scarce resources.

The possibility of attending secondary care facilities was prohibited by the cost of transport along with the ability to pay for medications, throwing light on the existence of significant disparities in access to health care. In addition, although CHW had been provided with a tablet for recording information on diabetes which could then be relayed to the local hospital, this was not the case for mental health. This supports the work conducted by Bosire et al. (2021) where health system challenges such as lack of collaborative care, an inconsistent supply of drugs and the re-assignment of tasks previously carried out by physicians all led to problems with health care delivery.

Our study provides important insights into the experiences of individuals living in rural communities in Kenya, however there were limitations to our work. The interviewees, in particular the HCW, may have felt challenged by the questions asked and concerned that they were being 'tested' on their knowledge of diabetes and depression. This was less apparent in those with these conditions although they may have seen this as an opportunity to express their concerns about the availability of services. It is hoped that our work addressing the existing negative conceptions and language used to describe diabetes and depression will challenge the myths and misconceptions and improve identification and treatment. Our work also has implications for future studies; the use of appropriate language and a wider understanding of the importance of the cultural context as well as working alongside members of the local community may have a significant impact on the design of future studies and the success of any interventions. At the same time however, scarcity of health care resources remains a critical barrier to addressing the needs of rural populations and improving the emotional and psychological impact of these long-term conditions.

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References

- Akena, D., Kadama, P., Ashaba, S., Akello, C., Kwesiga, B., Rejani, L., Okello, J., Mwesiga, E. K., & Obuki, E. A. (2015). The association between depression, quality of life and the health care expenditure of patients with diabetes mellitus in Uganda. *Journal of Affective Disorders*, 174, 7–12. <https://doi.org/10.1016/j.jad.2014.11.019>

- Akena, D., Okello, E. S., Simoni, J., & Wagner, G. (2020). The development and tailoring of a peer support program for patients with diabetes mellitus and depression in a primary health care setting in Central Uganda. *BMC Health Services Research*, 20(1), 436. <https://doi.org/10.1186/s12913-020-05301-7>
- Backe, E. L., Bosire, E. N., Wooyoung Kim, A., & Mendenhall, E. (2021). "Thinking too much": A systematic review of the idiom of distress in Sub-Saharan Africa. *Culture, Medicine, and Psychiatry*, 45(4), 655–682. <https://doi.org/10.1007/s11013-020-09697-z>
- Bosire, E. N., Lindile, C., Xola, P., Cho, A., & Mendenhall, E. (2021). God, church water and spirituality: Perspectives on health and healing in Soweto, South Africa. *Global Public Health*, <https://doi.org/10.1080/17441692.2021.1919738>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Céna, J. M., Noorishad, P. G., Kokou-Kpolou, C. K., Dalexis, R. D., Hajizadeh, S., Guerrier, M., Clorméus, L. A., Bukaka, J., Birangui, J. P., Adansikou, K., Ndengeyngoma, A., Sezibera, V., Derivois, D., & Rousseau, C. (2021). Prevalence and correlates of depression during the COVID-19 pandemic and the major role of stigmatization in low- and middle-income countries: A multinational cross-sectional study. *Psychiatry Research*, 297, 113714. <https://doi.org/10.1016/j.psychres.2021.113714>
- Green, B., & Colucci, E. (2020). Traditional healers' and biomedical practitioners' perceptions of collaborative mental healthcare in low-and middle-income countries: A systematic review. *Transcultural Psychiatry*, 57(1), 94–107. <https://doi.org/10.1177/1363461519894396>
- Halcomb, E. J., Gholizadeh, L., Digiacomo, M., Phillips, J., & Davidson, P. M. (2007). Literature review: Considerations in undertaking focus group research with culturally and linguistically diverse groups. *Journal of Clinical Nursing*, 16(6), 1000–1011. <https://doi.org/10.1111/j.1365-2702.2006.01760.x>
- International Diabetes Federation Atlas. (2019). <https://www.diabetesatlas.org/en/>.
- Kagee, A., & Le Roux, M. A. (2009). Person-centred counselling to ameliorate symptoms of psychological distress among South African patients living with hypertension and diabetes: Results of an intervention study. *Family Practice*, 51, 206–210. <https://doi.org/10.1080/20786204.2009.10873849>
- Kar, S. K., Oyetunji, T. P., Prakash, A. J., Ogunmola, O. A., Tripathy, S., Lawal, M. M., Sanusi, Z. K., & Yasir Ararat, S. M. (2020). Mental health research in the lower-middle-income countries of Africa and Asia during the COVID-19 pandemic: A scoping review. *Neurology, Psychiatry and Brain Research*, 38, 54–64. <https://doi.org/10.1016/j.npbr.2020.10.003>
- Lloyd, C. E., Nouwen, A., Sartorius, N., Ahmed, H. U., Alvarez, A., Bahendeka, S., Basangwa, D., Bobrov, A. E., Boden, S., Bulgari, V., Burti, L., Chaturvedi, S. K., Gaebel, W., de Girolamo, G., Gondek, T. M., Guinzbourg de Braude, M., Heinze, M. G., Ji, L., Hong, X., ... Xin, Y. (2018a). Prevalence and correlates of depressive disorders in people with type 2 diabetes. Results from the International prevalence and treatment of diabetes and depression (INTERPRET-DD) study; a collaborative study carried out in 14 countries. *Diabetic Medicine*, 35(6), 760–769. <https://doi.org/10.1111/dme.13611>
- Lloyd, C. E., Sartorius, N., Cimino, L. C., Alvarez, A., Guinzbourg de Braude, M., Rabbani, G., Uddin Ahmed, H., Papellbaum, M., Regina de Freitas, S., Ji, L., Yu, X., Gaebel, W., Mussig, K., Chaturvedi, S. K., Srikanta, S. S., Burti, L., Bulgari, V., Musau, A., Ndeti, D., ... Mankovsky, B. (2015). The INTERPRET-DD study of diabetes and depression: A protocol. *Diabetic Medicine*, 32(7), 925–934. <https://doi.org/10.1111/dme.12719>
- Lloyd, C. E., Whicher, C., Wilson, A., Holt, R. I. G., & Kar, P. (2018b). Language matters; a UK perspective. *Diabetic Medicine*, 35(12), 1635–1641. <https://doi.org/10.1111/dme.13801>
- Lund, C., Tomlinson, M., De Silva, M., Fekadu, A., Shidhaye, R., Jordans, M., Petersen, I., Bhana, A., Kigozi, F., Prince, M., Thornicroft, G., Hanlon, C., Kakuma, R., McDaid, D., Saxena, S., Chisholm, D., Raja, S., Kippenwood, S., Honikman, S., ... Patel, V. (2012). PRIME: A programme to reduce the treatment gap for mental disorders in five low-and middle-income countries. *PLOS Medicine*, 9(12), e1001359. <https://doi.org/10.1371/journal.pmed.1001359>
- Mendenhall, E., Kohrt, B. A., Norris, S. A., Ndeti, D., & Prabhakaran, D. (2017). Noncommunicable disease syndemics: Poverty, depression, and diabetes among low-income populations. *Lancet*, 389(10072), 951–963. [https://doi.org/10.1016/S0140-6736\(17\)30402-6](https://doi.org/10.1016/S0140-6736(17)30402-6)
- Mendenhall, E., Rinehart, R., Musyimi, C., Bosire, E., Ndeti, D. M., & Mutiso, V. M. (2019). An ethnopsychology of idioms of stress in urban Kenya. *Transcultural Psychiatry*, 56(4), 620–642. <https://doi.org/10.1177/1363461518824431>
- Moasun, F. Y., & Mfofo-M'Carthy, M. (2020). The power of the tongue: Inherent labeling of persons with disabilities in proverbs of the Akan people of Ghana. *Qualitative Social Work*, 20(4), 911–927. <https://doi.org/10.1177/1473325020910469>
- Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: Results from the World Health Surveys. *The Lancet*, 370(9590), 851–858. [https://doi.org/10.1016/S0140-6736\(07\)61415-9](https://doi.org/10.1016/S0140-6736(07)61415-9)
- Musyimi, C. W., Mutiso, V. N., Musau, A. M., Matoke, L. K., & Ndeti, D. M. (2017). Prevalence and determinants of depression among patients under the care of traditional health practitioners in a Kenyan setting: Policy implications. *Transcultural Psychiatry*, 54(3), 285–303. <https://doi.org/10.1177/1363461517705590>

- Mutiso, V., Gitonga, I., Musau, A., Musyimi, C., Nandoya, E., Rebello, T., Pike, K. M., & Ndetei, D. M. (2018). A step-wise community engagement and capacity building model prior to implementation of mhGAP-IG in a low-and middle-income country: A case study of Makueni County, Kenya. *International Journal of Mental Health Systems*, 12(1), 57. <https://doi.org/10.1186/s13033-018-0234-y>
- Mutiso, V., Pike, K. M., Musyimi, C., Gitonga, I., Telea, A., Rebellob, T. J., Thornicroft, G., & Ndetei, D. (2019). Feasibility and effectiveness of nurses and clinical officers in implementing the WHO mhGAP intervention guide: Pilot study in Makueni County, Kenya. *General Hospital Psychiatry*, 59, 20–29. <https://doi.org/10.1016/j.genhosppsych.2019.04.005>
- Mutiso, V. N., Musyimi, C. W., Nayak, S. S., Musau, A. M., Rebello, T., Nandoya, E., Tele, A. K., Pike, K., & Ndetei, D. M. (2017). Stigma-related mental health knowledge and attitudes among primary health workers and community health volunteers in rural Kenya. *International Journal of Social Psychiatry*, 63(6), 508–517. <https://doi.org/10.1177/0020764017716953>
- Myers, B., Petersen-Williams, P., van der Westhuizen, C., Lund, C., Lombard, C., Joska, J. A., Levitt, N. S., Butler, C., Naledi, T., Milligan, P., Stein, D. J., & Sorsdahl, K. (2019). Community health worker-delivered counselling for common mental disorders among chronic disease patients in South Africa: A feasibility study. *BMJ Open*, 9 (Suppl 3), 1. <https://doi.org/10.1136/bmjopen-2019-030833>
- Ndetei, D. M., Khasakhala, L., Kuri, M., Mutiso, V., Ongecha, F. A., & Kokonya, D. (2009). The prevalence of mental disorders in adults in different level general medical facilities in Kenya: A cross-sectional study. *Annals of General Psychiatry*, 8(1), 1. <https://doi.org/10.1186/1744-859X-8-1>
- Shirey, K., Manyara, S. M., Atwoli, L., Tomlin, R., Gakinya, B., Cheng, S., Kamano, J., Laktabai, J., & Pastakia, S. (2015). Symptoms of depression among patients attending a diabetes care clinic in rural western Kenya. *Journal of Clinical and Translational Endocrinology*, 2(2), 51–54. <https://doi.org/10.1016/j.jcte.2015.02.002>
- Snoek, F. J., Bremmer, M. A., & Hermanns, N. (2015). Constructs of depression and distress in diabetes: Time for an appraisal. *The Lancet Diabetes & Endocrinology*, 3(6), 450–460. [https://doi.org/10.1016/S2213-8587\(15\)00135-7](https://doi.org/10.1016/S2213-8587(15)00135-7)
- Van der Feltz, C. M., Nuyen, J., Stoop, C., Jacobson, A. M., Katon, W., Snoek, F., & Sartorius, N. (2010). Effect of interventions for major depressive disorder and significant depressive symptoms in patients with diabetes mellitus: A systematic review and meta-analysis. *General Hospital Psychiatry*, 32(4), 380–395. <https://doi.org/10.1016/j.genhosppsych.2010.03.011>
- World Health Organisation. (2010). Intervention Guide for mental, neurological and substance use disorders in non-specialized health settings. Retrieved April 4 2021, from https://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/.
- World Health Organisation Mental Health Atlas. (2020). Geneva: World Health Organization; 2021.