

# Measuring and Understanding Depression in Women in Kisoro, Uganda

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**Abstract** Depression is highly prevalent and the cause of considerable suffering for peoples across the globe. Case finding for depression is challenging because individuals often do not recognize the symptoms in themselves or may resist the diagnosis as a result of cultural stigma. Screening instruments, to be accurate, must be valid in the particular setting in which they are being applied, and diagnosis in primary care settings, is further made challenging because patients often present with a wide variety of somatic symptoms that could be medical. 115 women were screened for depression in this study in one community in Uganda, and 87 were found to be depressed using the SRQ-20. The cognitive impairment and decreased energy sub-scales of the SRQ-20 seemed to best differentiate for depression. We then interviewed the 87 women and found that, overwhelmingly, their complaints were somatic, and that their expectation for treatment was to receive medical tests and medications. Caregivers in primary care clinics in Uganda should know that in the reporting of their somatic symptoms patients may be trying to communicate

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more about themselves than just the state of their physical health; and that feelings of uselessness or of hopelessness when expressed by a patient should lead them to suspect severe mental illness since these symptoms were not found to be characteristic of the milder depression that is highly prevalent in Ugandan women.

**Keywords** Diagnosis · Depression · Somatic idiom · Uganda · Distress idioms · Explanatory models

## Introduction

This paper describes an exploratory study of depression in Ugandan women in the community and in primary care clinics focusing on how their symptoms can best be assessed by caregivers. This is important because similar sounding somatic symptoms can as easily be brought on by chronic stress or depression as by untreated medical illness. Also, patients whose somatic symptoms are non-pathological need to be sorted out by caregivers from patients whose symptoms are signals of mental illness. This line of inquiry is needed because caregivers in primary care clinics in Uganda have indicated that they are struggling with these issues and want better guidance (Kigozi et al. 2016:s42).

## Study Description

### Objective

#### *The Setting*

This study was entered into as part of an ongoing cooperative partnership between the Mutolere Hospital district hospital in Kisoro, Uganda in the rural southwest of Uganda, near the border with Rwanda, and the University of Connecticut School of Medicine. The study focused on women in their prime “child-bearing years” of 18–35 since it is plausible that mental health issues are particularly relevant to this age group because these are the years when women have multiple stressors in their lives. The study was conducted over a nine-day period in July of 2014 in three settings: a post-natal clinic at the district hospital in the town of Kisoro, (Public Health Clinic at Mutolere Hospital, abbreviated as PHC at MH), a primary care clinic outside of town (Clare Nsenga clinic or CNC), and in and around a women’s center in the rural outskirts (Kyibumba Young Women Community Based Development Initiative or KYB). The locations were chosen to capture a demographically varied range of women all seeking some form of care in their community.

#### *The Sample*

We used a non-probability convenience sample. Young women who looked to be in the target age range of 18–35 were approached by a Ugandan female study team

member. Women under 18 and over 35 years of age were not included. Potential recruits were read a prepared script in the local language of Rufumbira and those who were found to be eligible and who agreed to participate were enrolled. There were no other criteria for enrollment. The total sample size was 115.

## Methods

### *The Study Design*

Following the collection of basic demographic and other descriptive data, each study participant's mental health status was measured using the Self-Reporting Questionnaire, (SRQ-20), a 20 items "Yes or No" research instrument developed using psychiatric morbidity instruments from a wide variety of cultural backgrounds and recommended by the WHO to screen for the common mental disorders (CMD) of anxiety and mild depression in the community (Abbo et al. 2009), and slightly modified for use in Sub-Saharan Africa (SSA) by Aidoo and Harpham (2001) (see "Appendix" for the questions). Each of the items on the SRQ-20 is scored 0 or 1. A score of 1 indicates that the symptom was present during the past month, a score of 0 indicates that the symptom was absent. The maximum score is therefore 20. Seven or higher is the cut-off for possible depression used by Aidoo and Harpham (2001), but other authors now advocate the use of a different cut—off point. Scholte et al. (2011) found that the SRQ-20 performed most reliably as a predictor of CMD in women, in a Rwandan community setting, when the cut-off point was set at 10. In our study, the SRQ-20 results are reported using both the 7 or higher, and the 10 or higher cut-off points, but the cut -off point for participants to proceed to the interview phase was 7 or higher.

Tafari et al. (1991), working with the SRQ-20 to screen for mental illness in a rural Ethiopian adult population, found three meaningful factors, "interference with intellectual and work functioning, emotionality and somatic expression" (p. 201) corresponding in the SRQ-20 to the three items in the cognitive domain which are "not thinking clearly" (8), "difficulty with decision making" (12) and "work suffering" (13); the four anxiety and depression items in the affective symptoms domain which are "crying more than normal" (10), "being unhappy" (9), "being frightened easily" (4) and "feeling worthless" (16); and the four items in the "somatic symptom" domain which are "headache" (1) lack of appetite" (2), "poor digestion" (7), "sleeping problems" (3). To this category, in the analysis of our study's data was added "having uncomfortable feelings in stomach" (19). In addition, there are the three items in the decreased energy domain: "being easily tired" (20), "always feeling tired" (18), "not enjoying activities" (11); and the four items in the depressive thoughts domain: "being unable to play a useful part in life" (14), "thinking of ending life" (17), "having lost interest in things" (15), and "being nervous, tense and worried" (6)." Hands shake" (5), an alcohol use disorder item, was felt to not be relevant to our study population and was not included in the analysis of our data.

In our study the SRQ-20 was administered in the local language of Rufumbira by a two -person study team consisting of a female Ugandan trained social worker and a United States trained female Advanced Practice Nurse Practitioner (APRN). Upon

completing the SRQ-20, participants who had scores of 7 or higher were asked if they would agree to be interviewed immediately. The interview consisted of a set of eight questions developed by Arthur Kleinman, and modified for use in Sub-Saharan Africa by Aidoo and Harpham (2001) (see “Appendix”). Arthur Kleinman is an American psychiatrist who is a leading expert in the field of transcultural psychiatry. Kleinman (1980) coined the term “explanatory model” to characterize concepts of illness of patients and their caregivers, specifically, questions such as “what name does your illness have?”, “how does it work?”, “what are the causes of it?”, “what impact does it have?”, “what is most feared about it?”, and “what should be done about it? Kleinman’s Eight Questions interview format has been an established research tool especially in psychiatry, a field in which the expression and articulation of symptoms vary so widely from one cultural context to another.

Mitchell Weiss’s Explanatory Model Interview Catalogue (EMIC) is an example of one of the research methods for eliciting explanatory models that has evolved since Kleinman. It combines open ended with direct questions with a system for coding the narrative data that permits results to be quantified (Medanth 2018). The EMIC enables comparisons between cultural contexts and reduces bias introduced as a result of the interviewer’s background and assumptions about illness such as, for example, the “primacy of the biomedical perspective (Medanth 2018:3). For our exploratory study on the clinical implications of illness meanings in one particular cultural context, we chose the original Eight Questions method. Having a locally based female Ugandan social worker with an empathetic style who is familiar with the issues (GM) administer all the interviews and translate them served to minimize over-simplification, stereotyping and confounding. A criticism of the open-ended Kleinman method is that “one cannot assume that failure to mention a particular aspect of distress, perceived cause, or help seeking experience means that these play no role in this person’s experience” (Weiss 1997:245). In our interviews, efforts were made to ensure understanding of questions by participants by providing examples of what we were looking for, and clarifying explanations were given when felt to be necessary. Also, follow up questioning by the interviewers was permitted when clarification of responses was sought. In other words, the Eight Questions format was not so rigidly adhered to as to be limiting. Privacy was assured for participants by conducting all interviews in a room behind a closed door when available, or in a cubicle set apart from others when the interview was conducted in a large waiting area.

Responses were recorded in English by hand by the APRN according to the translation from the Rufumbira provided by the Ugandan social worker. Patient narrations were in the third person, the interviewer’s field notes of the participant’s words. Study materials were kept in a secure location at all times and analyzed some months later by the investigators in the US. Analysis of transcribed interviews followed a grounded theory approach as common themes were allowed to emerge from the qualitative data (Medanth 2018:4). Overall, the Kleinman interview proved to be easy to learn and teach, quick to administer, and because the questions are open-ended, especially appropriate for a hypothesis generating study such as ours. In addition to guiding the interviews, the Kleinman questions serves as a useful framework for summarizing the qualitative data. Our discussion section frames the interview results using the Kleinman questions.

The open-ended Kleinman questions uncovered and illuminated the meaning of the women's "distress idioms". Idioms of distress were described by their inventor, Mark Nichter, a sociocultural anthropologist as follows:

In any given culture, a variety of ways exist to express distress. Expressive modes are culturally constituted in the sense that they initiate particular types of interaction and are associated with culturally pervasive values, norms, generative themes, and health concerns.

as cited in Hinton and Lewis-Fernandez (2010:210). Psycho-social distress has been shown in various cultures to be communicated often by symptoms experienced in the body, in other words, in a somatic idiom. Culture, was said by the historian, Edward Shorter, to influence symptom expression in such a way as to allow only the most "socially correct" behaviors to be exhibited (Bagayogo et al. 2013:65). The somatic idiom seems to have evolved in the world as a socially and culturally acceptable way for mental distress to be encoded and transmitted. Various such somatic idioms and their use by women especially in low and middle-income countries (LMICs) have been documented (Patel et al. 1999). In summary, representations of distress depend on cultural issues and there is therefore the need for locally situated models to understand the manifestations of illness in a particular setting.

While idioms of distress is not a new concept, and while it has been well established that non-western cultures somaticize psychological symptoms, using the concept here is useful because the purpose of our study is not only to demonstrate that the Ugandan women expressed their symptoms in somatic terms, but, also, to identify the commonly used terms that could serve as guidance for future diagnosis or treatment. Therefore, while the concept itself is not unique, its use in this context provides important information for clinical care.

### *Ethics Approval*

Ethical approval for the study was obtained from St Francis Mutolere Hospital in Kisoro, Uganda and the IRB at University of North Carolina-Chapel Hill. Once recruited, enrollees first participated in an informed consent process in which they were read a version of the informed consent document that had been translated into Rufumbira by our Ugandan study member which stressed that participants should expect to receive no treatment or other personal benefit as a result of their participation in the study, and that their participation was voluntary, and that no information identifying the participants by name or in any other way would appear in the report.

## **Results**

### **Characteristics of Study Participants**

Table 1 presents some summary characteristics of the study participants. Ages for the 115 study participants were distributed evenly across the desired age range. Of

**Table 1** Description of study population by site ( $n = 115$ )

	CNC	PHC at MH	KYB
N <sup>a</sup>	11	56	48
Average age	26.18 ± 5.21	24.95 ± 4.65	27.70 ± 5.34 ( $N = 47$ )
Percent married	0.727	0.872	0.745
Percent primary school or less	0.917	0.764	0.854
Percent employed outside the home	0.100	0.089	0.100
Percent partner employed	0.500	0.347	0.231
Average number of children	1.72 ± 1.49	2.38 ± 1.79	3.23 ± 2.26
Percent household size greater than 5	0.273	0.286	0.566

<sup>a</sup>Missing data points reduce the  $N$  in some calculations

the 115, seventeen participants had a secondary school education and four had a university education. Thirty-eight were married and fifty-five had a long-term partner, combined in the table under “married”. Over half of the women had three or fewer children. Seven had more than six children. Twenty-one of the women had a husband or partner who was working full time, and fifteen lived in a household with eight or more members. Therefore, even though the sample was purposive, we have achieved a fair degree of diversity among the participants.

The three study locations provided very different services. The women at the PHC at MH were there for a post-partum check with their baby. Their lives were organized enough to make it into town on the day of their participation in the study for a preventive health care visit. By contrast, many of the women who participated in the study at the KYB women’s center were members of the community who just happened to be passing by, and who agreed to participate. Despite these differences, overall, no statistical difference was found in most of the background and demographic characteristics of participants from the three locations. On age though, there is a significant difference at 95% confidence in the ages of the participants between PHC and KYB with KYB population being the older of the two by about 3 years in the average. On household size also, there is a statistically significant difference between PHC at MH and KYB ( $p$  value = 0.0043) The KYB population has the larger household size. On number of children, there is a difference approaching significance, between CNC and KYB. ( $p = 0.0626$ ). Women who participated in the study from KYB had more children and larger households, both of which can be explained by the age difference.

### *Analysis of SRQ Data*

The total of number of “yes” answers given to each of the SRQ 20 items by the 115 study participants is shown in Table 2. The SRQ-20 items most commonly responded to with a “yes” were “headache” (79) and “stomach problems” (76), followed by “not thinking clearly” (73), “feeling nervous” (70), “always feeling

**Table 2** Total Number of Study Participant “Yes” Answers by SRQ Item ( $n = 115$ )

SRQ item	Number of yes answers
1. Headache	79
2. Lack of appetite	60
3. Sleeping problems	55
4. Being frightened	53
5. Shaking hand	36
6. Feeling nervous	70
7. Poor digestion	58
8. Not thinking clearly	73
9. Being unhappy	62
10. Crying more than normal	54
11. Not enjoying activities	57
12. Difficulty with decision making	63
13. Work suffering	69
14. Unable to play useful part in life	49
15. Lost interest in things	67
16. Feeling worthless	39
17. Thinking of ending life	22
18. Always feeling tired	69
19. Stomach problems	76
20. Easily tired	60

tired” (69), “work suffering” (69), “lost interest in things” (67), “difficulty with decision making” (63), and “lack of appetite” (60).

Analysis of the average number of “yes” answers by site, and of the percent of respondents who said “yes” on 7 and 10 items of the SRQ 20 Questionnaire is shown in Table 3. There are some significant differences between the sites. On average number of items with “yes” answers, there is a statistically significant difference between PHC at MH and KYB ( $p = 0.0009$ ), with the women at KYB giving more “yes” answers. On the percent of respondents who said yes” on 7 items, there is also a statistically significant difference between PHC at MH and KYB ( $p = 0.0001$ ). KYB had the higher percent of respondents who said “yes”. On percent of respondents who said “yes” on 7 items, there is also a statistically significant difference between CNC and KYB ( $p = 0.0049$ ). KYB had the higher percent of respondents who said “yes”. On percent of respondents who said yes” on 10 items, there is also a statistically significant difference between PHC at MH and KYB ( $p = 0.0016$ ). KYB had the higher percent of respondents who said “yes”. On percent of respondents who said yes” on 10 items, there was no difference between CNC and KYB. The rank order from fewest to most on “yes” answers to items on the SRQ-20 depression scoring instrument is PHC at MH to CNC to KYB. From this data and from what is known about the sites from Table 1, it is possible to speculate that women in the more rural site (KYB) had greater family burdens since

**Table 3** Average number of items with “Yes” answers and percent of respondents who said “Yes” on 7-items and percent of respondents who said “Yes” on 10-items by site

Site	N	Average number of items with “Yes” answer	Percent of respondents who said “Yes” on 7 items	Percent of respondents who said “Yes” on 10 items
CNC	11	9.18	0.636	0.545
PHC at MH	56	8.68	0.618	0.473
KYB	48	12.27	0.939	0.776

**Table 4** Percent of respondents answering “Yes” by SRQ-20 domain by site

	N	Cognitive	Affective	Somatic	Decreased energy	Depressive thoughts
CNC	11	0.515	0.364	0.659	0.394	0.500
PHC at MH	55	0.448	0.377	0.545	0.461	0.395
KYB	49	0.789	0.556	0.638	0.660	0.505

they were older, had fewer resources and were more likely to respond positively to the depression-related items on the SRQ-20.

The percent of respondents answering “Yes” by SRQ-20 domain by site is shown in Table 4. These percentages were arrived at by calculating the percent of “Yes” answers for each item in the domain and then taking the mean of these percentages. Results show that there is a significant difference at 95% confidence between the PHC and the KYB women’s center on the percentage of women who indicated cognitive impairment ( $p$ -value = 0.0004) and on the percentage of women who indicated decreased energy ( $p$ -value = 0.0415). The difference between the percentage of women at PHC and KYB who indicated affective symptoms approached statistical significance ( $p$ -value = 0.0676) at 95% confidence.

The percentage of women who indicated somatic symptoms was high at all three sites and in about the same range: 54% at PHC, 64% at KYB and 66% at CNC. The percent with somatic symptoms is not highest at KYB, the most socioeconomically disadvantaged site, where depression was most prevalent and severe. That such high levels of somatic symptoms were detected in this study from a convenience sample of the community suggests that the reporting of somatic symptoms is common across the general population. Somatic symptoms do not correlate with depression leading to the conclusion that women reporting somatic symptoms alone are not depressed. What seems to differentiate better for depression are the domains of cognitive impairment and decreased energy and also, possibly, affective symptoms.

What is true for somatic symptoms is also true for the domain of depressive thoughts: no statistical difference between the three sites. However, the domain of depressive thoughts includes four distinct items, and the breakdown of the items within the domain does show some other interesting differences. Two of the items that make up the depressive thoughts domain, “lost interest in things” (15), and “feeling nervous, tense or worried” (6) can fairly be said to represent milder depression symptoms while the other two depressive thoughts items, “thinking of



ending life” (17) and “unable to play useful part in life” (14) can fairly be said to represent more severe depression symptoms. ANOVA analysis comparing the proportion of women who say “yes” to the first two items with the proportion of women who say “yes” to the second two items shows rejection of the null hypothesis at a confidence of 95% ( $p < 0.0001$ ) In this analysis the proportion of women that said “yes” to “feel that you are a worthless person” (16), an affective symptom typically associated with severe depression is also statistically lower at 95% confidence ( $p < 0.0001$ ) compared to the proportion who said “yes” to items 15 and 6. So, while there is a high percentage of women saying that they are stressed (61%) or have lost interest (58%), there is a lower percent of women who say “yes” to being unable to play a useful role in life (43%), or who feel like a worthless person (34%) or who acknowledge having thoughts of ending their life (19%). In summary, while a majority percent of women report generic symptoms that may be identified with depression, a significantly smaller percent actually report symptoms that are identified with clinical depression.

### *Analysis of Interview Data*

87 of the 115 study participants (75%) went on to the interview phase after scoring above the cut-off for possible depression in the initial stage of the study. Qualitative data gleaned from the interviews conducted in this study are detailed in Tables 5, 6 and 7): Problem or symptom description is in Table 5; illness causation is in Table 6; and course, consequence, expectations for treatment, and expected outcome and impact of condition are in Table 7. The data is divided into categories, and the total of the number of participants who meet criteria for each category is displayed in the tables as are illustrative sample narratives followed in the tables as well as in the text, in parenthesis, by the name of the study site where the participant was interviewed.

### *Distress Symptoms (Table 5)*

Fully 81 of the 87 interview phase participants (93%) reported at least one somatic symptom, and 31 (35%) reported five or more. Of the non-specific physical complaints reported by participants, the most common were aches and pains including headache, back pain, joint pain, tonsil pain, body aches, limbs feel paralyzed. The next most common were a variety of gastro-intestinal complaints including weight loss and poor appetite. The majority were stomach ulcers and stomach pain, often offered, by way of explanation by women, as associated with their not getting enough to eat, or not having enough time to eat during the course of their busy day. The next most common categories of symptoms were weakness or decreased energy, difficulty sleeping followed by a variety of gynecologic symptoms, heart symptoms, mostly palpitations, dizziness, insects crawling on skin, itchy skin and miscellaneous respiratory symptoms, including increased spitting and throat pain. Of those who reported a specific disease process, parasites were the most common, followed by HIV, seizure disorder and injuries. Aches and pains are associated with backbreaking work in the fields, or with fetching water:

**Table 5** Distress symptoms of participants screening positive for depression

Symptom or problem	Number reporting <i>N</i> = 87	Sample narratives
<b>Somatic complaint</b>		
Aches and pains	68	If back pain continues she fears she will have mental illness (PHC)
Gastro-intestinal distress	67	Too much gas since childhood, maybe from worms, <i>being worried all the time that people might talk about her because of her big stomach</i> (KYB)
Weakness and tiredness	57	<i>Has a sleeping sickness, feels sleepy</i> (KYB)
Weight loss	34	Stomach ulcers from not having what to eat; at times can have [food] for the children only (KYB)
Dizziness	13	Family planning injections given every three months causing <i>dizziness</i> and back pain (KYB)
Heart	12	Fear causes her to have <i>trouble breathing</i> , fear of getting beaten by her family, fears that boys can rape her when walking alone on the road; wants medicine for fear, hopes that her <i>heart</i> will relax, and she can be comfortable (KYB)
<b>Mental symptom</b>		
Not being at peace/stress	14	<i>Lack of peace</i> , even when she is sleeping (KYB)
Affective symptoms	6	Eg. Tears flow (PHC,15), Too many thoughts (KYB,12)
<b>Behavioral symptom</b>		
Lack of appetite		<i>Decreased appetite for husband</i>
For food	24	He will look for other women; she <i>hates herself</i> , not worthy of being with others, stressed (PHC,17)
For husband/sexual	2	
Lack of sleep	12	She <i>loses sleep</i> because of so many thoughts in her head (KYB)

“She miscarried because she was doing a lot of work and carrying baby on her back with a wrap around the abdomen; dizziness cause by the headaches and walking in the sun; thinks she might die”. Stomach ulcers, a frequent complaint, are often associated in the narratives with not having enough time to eat due to heavy workload, or with not having enough to eat: “Stomach ulcers, not eating on time, started when she got married, lot of work and no time to eat” (KYB).

Of the mental symptoms offered, chronic stress, often expressed in the idiom, “being without peace” is the most common, reported by 16%. For example, one woman said: “{T}he husband contributed to the death of her father in law and his death may have contributed to her being not at peace with her husband. At one time he threatened to kill her also” (KYB). 27% reported poor appetite for food, and 2% decreased libido. The distress idiom, “lacks appetite for husband” is a good example of a somatic representation of a social problem, as in the following narrative: “Has decreased appetite for husband, fears that husband will leave her

**Table 6** Cause of distress

Categories	Number reporting <i>N</i> = 87	Sample Narratives
Specific medical condition	16	Stressed by harassment she receives from her late husband's family, she contracted <i>HIV</i> from her husband; loss of appetite, loss of energy (PHC)
Marital problem	46	<i>Husband drinks a lot and refuses to work to give her money</i> to buy food and basic necessities. She has no house, no bed and no blankets. She would like an opportunity to work so that she can at least look after the family (PHC). She grew up an orphan and has had a lot of suffering and continued to have suffering after getting married (KYB)
Overwork	40	Not eating on time, <i>forcing herself to get her work done</i> (PHC)
Do not know	31	Does not know what the problem is, only that it will kill her because <i>the treatment is not working</i> (CNC)
Environmental cause	21	She fears that <i>heavy lifting has caused polio</i> , cannot work in the garden digging (PHC). From using a <i>public toilet</i> (PHC)
Mental problem	19	<i>Low self-esteem, hates herself</i> ; cannot feed on the right breast, cannot do all her work when she is pregnant as other women seem able to do, husband hates her because of her illness, he does not take care of her (PHC,18)
Poverty	13	Husband does not give care; she has been <i>depressed</i> since she got married over 15 years ago; <i>if there is a medicine that cures poverty, she will get healed and have peace because poverty is the main cause</i> (KYB,13)
Difficult pregnancy or child birth	12	When they pushed some machines through her vagina <i>checking her uterus, it might have caused her to have pain</i> because before, she had no pain. She thinks they might have bewitched her (KYB)
Witchcraft	10	Had a <i>severe mental health problem</i> , lasting 1 and 1/2 year, she went to a local doctor who healed her; <i>was bewitched</i> but does not know why. Dropped out of school, parents paid for her to have the spell to be taken off her, and now cannot afford to pay for her school (CNC,15)
Family planning	7	She thinks its <i>family planning</i> that has caused her pain, and she fears to be in the public, thinking they will talk about her (KYB)

**Table 7** Course, consequence, expected treatment, outcome and impact of problem/condition

	Number reporting <i>N</i> = 87	Sample narratives
Fears that problems will result in disability or death	70	Fears that if she becomes dizzy while in the garden no one can pick her up and <i>she will die</i> (PHC). <i>Epileptic</i> , fears will have seizure and die (PHC)
Fears that children will be orphaned or not well cared for	17	Has HIV, from husband who worked in Kampala and was with other women; fears that she will be bed ridden and no one will help her, and <i>her children will suffer</i> (KYB)
Worries about husband's extra-marital habits	4	
Fears sterility	6	Has <i>not been able to conceive</i> since her first child, fears that she is sterile; wants x ray so she can find out what is wrong, and medicine so she can conceive and feel better (KYB)
Work affected due to problem	34	Fears that <i>when she is carrying something heavy</i> her back will crack and break (KYB)
Family affected due to problem	10	When she argues with husband, she gets headaches; if headache continues, she fears that she will have a mental illness. Thinks about leaving her partner, getting an opportunity to work. If she can work, she can take care of the family and she won't have to think about leaving her partner (PHC)
Opportunity to work	3	
Emotions or cognitive faculties affected due to problem	13	<i>She hates herself</i> (KYB,18) Has bad dreams, is being chased, sleepless nights, her brother used to beat her with a stick, quarreled over access to parent's land and harvest, he threatens to kill her, <i>she is unable to think clearly</i> , requests x ray to diagnose what is wrong with her brain (PHC)
Physical health affected due to problem	55	Lower abdominal pain. When she goes to the hospital, she is given <i>medicine for ulcers and she feels better for a while</i> (KYB)
Investigations and/or medications requested	66	Thinks <i>medicine</i> may bring change in her life and she becomes again strong (KYB) Stress has caused all the diseases that she is suffering from: nausea, gas, backache, lack of energy, paralysis. <i>Still she wants an x-ray</i> to find out what is really wrong with her (KYB)
To get better	72	Stomach ulcers, not eating on time, started when she got married, lot of work and no time to eat, <i>she will receive any kind of medicine that is given to her as long as it works.</i> (KYB,)
Has lost hope	1	Urinary incontinence following a bicycle accident over 10 years ago, soils her clothes does not go out much and fears that if she gets married, the husband will reject her. She has been to the hospital in Kampala but treatment with medicine did not work. <i>She has given up and has lost hope</i> (PHC,15)

because she does not have feelings for her husband, he will look for other women, she hates herself, not worthy of being with others, stressed” (PHC).

Analysis of the narrative data reveals that symptoms of stress and anxiety are often attributed to the heart or chest as in the following:” Quarreled with husband, heart rotates a lot, fears it will come out” (KYB). Most women express in a somatic idiom the mental distress that they are experiencing: “when she argues with husband, she gets headaches; if headache continues, she fears that she will have a mental illness” (PHC).

Only eight of the eighty-seven participants who scored above the cut-off for possible depression (9.2%) admitted to symptoms more often directly associated with “mental illness” or described themselves as being “depressed “or as having a “serious mental health problem”. These symptoms include: “is depressed “, “hates herself”, “low self-esteem”, “has given up and lost hope” and the mental distress idioms, “tears flow” and “too many thoughts in head”. Symptoms of headache (32%) and insomnia (14%) figure prominently as idioms of life problems, as in the following sample narratives: “Headaches from too much hair on head and no money to go to barber, tears flow from the eyes” (PHC); and “She loses sleep because of so many thoughts in her head” (KYB)

### *Causal Models (Table 6)*

Data about causal models stem from responses to Kleinman interview question 2, “What do you think has caused your problem?” and question 3, “Why do you think it started when it did? Results are shown in Table 6. A majority of women reported that their problem was with their husband, giving responses such as: he does not help, husband beats her, she has negative feelings towards husband, husband drinks, husband does not give money, problems began after marriage, rival women: “stomach pain from parasites and vaginal infection; and joint pains; husband is bringing her infection, fears that sickness will kill her and wants husband to get the treatment and counseling for candida infection” (PHC).

Nearly half of the women (46%) reported excessive workload to be a cause of their symptoms or problems. Included in this are work is too hard, or too physical, does not eat on time due to work, or has no time or energy to eat or care for self, or for house or children. Poverty and other environmental factors, pointed to in the narratives, reflect the harshness of life, and include inadequate housing, lack of food or bad food, and bad drinking water.

She does not know but thinks it’s worms from eating sweet potatoes that have caused the stomach ulcers that will kill her (CNC)

If there is a medicine that cures poverty, she will get healed and have peace because poverty is the main cause (KYB)

Women attributed their symptoms of poor health to a range of other causes. Persistent difficulties from complications of childbirth, and complaints about side effects as a result of family planning injections or procedures were a common theme: “during tubal ligation there was damage to the blood vessel which causes

back and leg joint pain and cold fingers and toes” (PHC). Some women believed in witchcraft and saw it as the cause. Other causes mentioned were being bewitched, in some cases by neighbors, neighbors jealous of their relative tranquility or prosperity: “feeling of insects crawling on her arms is a sign that she has been bewitched because she has peace with her husband and family and someone was jealous of her, it happened 5 years ago” (CNC). It is customary to attribute mental problems to witchcraft: “had a severe mental health problem, lasting one and one-half years, she went to a local doctor who healed her was bewitched but does not know why. Dropped out of school, parents paid for her to have the spell to be taken off her, and now cannot afford to pay for her school” (CNC). “Do not know” was the third most common response of women to the question about cause (36%). Only one participant described her problem as “depression” and one spoke of having had a “serious mental health condition”.

*Course, Consequence, Expected Treatment, Outcome and Impact of Condition (Table 7)*

Participant responses to Kleinman interview Questions 4 through 8 (Questions are listed in “[Appendix](#)”) are the source of data regarding problem impact. Common fears and worries of our participants were the following: dying prematurely (57%) with consequence of children suffering or becoming orphans, being unable to care for children; having cancer or losing good health to some other medical condition (40%), and, consequently, not being able to carry on with one’s daily activities due to physical problems; rape, infidelity, STD’s or dissolution of marriage (11%); miscarrying, being unable to conceive or becoming useless in some other way (8%). An example of a somatic idiom that seems to encompass the commonly held fear of becoming disabled or dying prematurely is the following: “Because she is losing the weight she will have other problems and she can die”.

As far as expectations of treatment is concerned, the majority of women in this study said that they hoped for or expected a cure or wanted to feel better (62%), wanted an x ray or medicine or both (76%). Others wanted a general exam of the body, wanted to find out what the real cause of the problem was, did not know what the right treatment was, wanted an opportunity to work. Only 2% said that they had lost hope of getting better or were not sure if they would get better or not. What comes through loud and clear from this data is that while most of the women are suffering desperately, most are actively looking for help so that they can feel and do better:

Stressed by harassment she receives from her late husband’s family, she contracted HIV from her husband; loss of appetite, loss of energy, *hopes that herbal medicine may work for her* because tablets have not been of good use for her (PHC)

Heart problems due to heavy work, heavy work started on an early age (age thirteen) when she got married, unable to daily activities due to heart problems, she fears that if heart problems continue she will not be able to work

and take care of the family (she is the bread winner in the family), *she thinks that with treatment she can get better*, do her daily activities, earn a living and take care of her family (KYB)

What comes across from the qualitative data is that most of the women are chronically stressed, chronically tired, in pain, worried about their health, worried about dying prematurely, and/or dissatisfied because the treatment they are receiving is not working. But, despite all this, most seem to be trying to keep up with all the jobs that are expected of them, and to be looking for the right treatment so that they can feel and do better. In other words, the qualitative data, echoing the quantitative data, is telling us that the large majority of women, while chronically stressed are not clinically depressed.

Severe depressive thoughts or affective symptoms such as “hate myself”, “feel not worthy of others” or “have given up hope” when reported by a woman to her caregiver should raise concern of a more serious mental disorder since, as shown by analysis of Table 2, expressions of self-loathing and self-doubt or of hopelessness (SRQ-20 Items 14, 16, 17) were rejected by the large majority of women in this study. In addition, women who describe themselves as having “depression” or a “mental health problem” when assigning the cause of their problem, should raise similar concerns on the part of caregivers since acknowledgment of mental illness as a cause of the problem (see Table 6) is also unusual. The mean SRQ-20 score of the eight women (6.9% of study population, 9.2% of population above the cut off for possible depression) who in the interviews acknowledged severe affective symptoms ( $N = 5$ ) is 15.4, which is higher than the average SRQ-20 score across the entire study sample ( $N = 115$ ) which is 10.2; higher than the average SRQ-20 score at KYB which was 12.3, higher than the average SRQ-20 score of the those above the cut-off for possible depression who went on to the interview stage ( $N = 87$ ) which was 12.6; and higher than the average SRQ-20 score of those who scored above the cut-off of 10 or higher ( $N = 67$ ) which was 13.8. (Refer to tables for these participants narratives, SRQ scores, and study location).

The particular depressive thoughts, and affective distress symptoms, “hate myself”, “have given up hope” and “feel not worthy of others” we hypothesize to be culturally salient idioms of distress, code words in this milieu for mental illness.

## Conclusion

Using the cut-off point for “case-ness” of 10 or higher recommended by Scholte, et al. (2011), the overall prevalence of “depression” in this sample was 61.3%, ranging from 47.3% at PHC at MH, to 54.5% at CNC to 77.6% at KYB. That such high levels of depression were detected in this study from a convenience sample of the community suggests a degree of diagnostic misclassification. Demographic data shows that the population of women at KYB is older and living in larger households, and perhaps taking care of more children than the population of women at the other two sites. It is plausible that these factors represent risk factors for depression that contribute, in the KYB population, to a higher prevalence of depression since

mental issues are particularly relevant, it seems plausible, when women have multiple stressors in their lives. Analysis of SRQ-20 sub-score domains and items by site suggests that somatic symptoms and the depressed thoughts domain as a whole do not differentiate as well for depression compared with decreased energy and cognitive impairment. The evidence for this is that, at KYB, where the prevalence of depression is highest and the level of depression most severe compared with the other sites, statistically more participants endorsed the latter two, but not the former two domains. In this analysis, there was a difference approaching statistical significance at KYB compared to PHC of the proportion of women endorsing affective symptoms.

Analysis of Table 2 indicates that while women feel tired, stressed, unhappy with how things are now and not always thinking clearly, they do not endorse more severe depressive symptoms that would identify them as having mental illness. This hypothesis is also borne out in the qualitative data of the eighty-seven women who scored above the cut-off for possible depression. The depressive thoughts that speak to feelings of hopelessness and uselessness and the affective symptom of feeling like a worthless person were not embraced by as many participants in this study. “Yes” response rates to these SRQ-20 items are statistically lower compared with “yes” response rates on other items. Interestingly, two syndromes of depression that are locally recognized, known, in the Luganda language, as *y’okwetchawa*, meaning ‘self-loathing’, and *okwekubaziga*, meaning ‘self-pity’, have been described (Verdelli et al. 2003). What we can hypothesize from our data is that the majority of women reject identifying with either of these two “depressive thoughts” that would label them in their culture as having a severe mental disorder. What seems to reflect from our results is how mental, spiritual and moral distress are acceptably expressed by women in this culture, and, on the other hand, what behaviors are stigmatized. More inquiry is needed into the full implications of concepts embodied by “self-loathing”, “self-pity”, “feeling worthless”, “unable to play useful role in life and “thinking of ending one’s life”.

The additional items that contributed to the diagnosis of depression came from the decreased energy, cognitive difficulties and possibly affective symptoms subscales, with women at the KYB center saying “yes” to more of these. It is possible from this study to propose a shortened version of the SRQ-20 instrument for depression screening in this milieu emphasizing the items from these three sub-scale domains.

Sample narratives from this study demonstrate over and over the link that women make in their own minds between the somatic symptoms that they report experiencing, and the everyday circumstances of their lives, particularly their marital problems and poverty. According to the OECD’s 2018 Social Institutions and Gender Index (SIGI) Uganda data file, attitudes that justify practices such as a girl’s early marriage, a husband’s beating his wife for specific reasons, denying a woman the right to decide about whether or not to use contraception, denying a woman the right to refuse sex with her husband, declaring that household and caring tasks should be performed by girls but not boys, land rights and management that are male dominated, and restricted access of women to justice, prevail in Uganda, especially in southwest Uganda where this study took place (OECD 2018). Domestic



violence and gender inequality are among the factors that have been shown to be social determinants of depression (Patel et al. 2010).

From the narratives we learn something about the everyday challenges faced by the women in this study, beset upon as some indicated that they are by a society that treats them in some cases very poorly. One woman said that she “has bad dreams, is being chased, sleepless nights, her brother used to beat her with a stick, quarreled over access to parent’s land and harvest, he threatens to kill her” (PHC). For a woman to say that she “hates herself” and feels that she is “not worthy of being with others” because she lacks “appetite for her husband” who is ‘looking for other women’ (PHC); or for another to say that she has “low self -esteem, hates herself, cannot feed on the right breast, cannot do all her work when she is pregnant as other women seem able to do” and that her “husband hates her because of her illness, he does not take care of her” (PHC) speaks loudly of gender inequality. When a woman “fears that boys can rape her when walking alone on the road” and “seeks medicine for her fear that will relax her heart” (KYB) it sheds light on what the root of the problem might be when a young woman comes into the clinic seeking medicine for her heart. A similar conclusion about the status of women is inescapable when a woman says that she is so overworked that she has no time to stop and eat. Or, from a woman reflecting on her husband who “drinks a lot and refuses to work to give her money” who says that she “would like an opportunity to work so that she can at least look after the family” (PHC).

In the both the quantitative analysis of the entire study population ( $N = 115$ ) and in the qualitative data analysis of the interviews ( $N = 87$ ), the somatic idiom was found to be highly prevalent. The somatic idiom seems to be how sub-clinical levels of distress find their expression among women in Uganda (Kirmayer et al. 1998:6) as elsewhere, the best available language to signal their predicament and, perhaps, to mobilize support. (Kirmayer et al. 1998:8). In this sense, the somatic idiom, widespread in the community among women, may be seen as not pathological, but, rather, as adaptive. Also, what seems apparent from the qualitative data is that while most of the women above the cut off for possible depression were indeed experiencing mental distress of one form or another, most still are managing to continue functioning in their daily lives; so struggling, yes, but depressed, no. For women in Uganda, as elsewhere, the somatic idiom may be the socially acceptable way for mental, spiritual, moral and physical distress to find expression, in general, and when speaking to caregivers in the clinic.

While the SRQ 20 item scores suggest that most women in the study are experiencing significant mental distress symptoms, interestingly, most had expectations of a medical approach to treatment. The narratives suggest that medical treatment seems to hold out to many the promise of a magical cure for their ills as illustrated by one woman who said that she “thinks medicine may bring change in her life, and she becomes again strong”.(KYB) Clinicians who are “unfamiliar with the social meanings “of the somatic idiom “may focus exclusively on the somatic dimensions and so contribute to patient’s bodily preoccupation” (Kirmayer et al. 1998:6).

In this study, the diagnosis of depression was made on the basis of the score on the SRQ-20. Admittedly, neither the condition being screened for, “depression”,

nor the screening instrument used are locally situated, and this is a weakness of the methodology. Using the SRQ-20, the majority of the women in this study screened positive for possible depression. In the interviews, the great majority of participants reported having somatic symptoms. In this study, somatic symptoms were so highly prevalent that they did not seem to differentiate well for the diagnosis of depression. Women who have somatic symptoms as a result of medical illness are not captured in this study and other primary care clinic-based studies with more of a focus on accurate diagnosis may be necessary to focus on the distinguishing features of patients with somatic idiom as an expression of life stress or depression versus those with somatic symptoms caused by medical illness. That this was largely a sample of women in the community who were not acutely ill makes medical illness as an explanation of the symptoms expressed by participants in this study somewhat less likely.

Lastly, in terms of flaws in the methodology of this study, the Explanatory Model framework, which neatly separates identity, cause, consequence, course, and treatment of “illness”, did not hold up in the sense that the same answer was often given by women to more than one or to several of the Eight Questions. The questions probe for links between illness and life problems. The link between health and life stress is a western concept that may not exist in Uganda. Did the women think they were being asked questions fundamentally about their health or about their life problems? The interview questions introduced concepts that must have been confusing to some women in some instances. The women talked to us about their life problems, about how they felt and struggled to keep up. Many indicated that their bodies were damaged, that they were suffering, that they had an undiagnosed and untreated medical condition. Only a very few saw themselves as having a mental problem. Despite the flaws in the methodology, findings from this study do clarify certain aspects and can serve as starting points for investigations into mental conditions recognized as problems by Ugandans using “locally meaningful categories” (Weiss et al. 1992:820).

A strength of our research methodology is that it set up two separate data streams to draw on. On the one hand, a broad array of quantitative SRQ-20 data yielded characteristics of the entire sample and also allowed for comparisons to be drawn between the three sites. This was combined with qualitative data that yielded rich detail about what individual women were experiencing. These two “lenses” through which to view the subject enhanced the power and perspective of our study. Our main conclusions about how women in Kisoro view their predicament comes as a result of the one stream of data elaborating on the other.

Findings from this study with possible significance for caregivers in Uganda include understanding that in the reporting of their symptoms patients may be trying to communicate more about themselves than just the state of their physical health. Asking your patients to tell you about what is going on in their life might be giving them just the permission to open up to you that they are looking for, and listening for a while can send a powerful message of caring which might make your patient feel better. Think of doing this, for example, when a patient with many physical complaints tells you that your medical treatment is not working. Every day anxiety and depression might be the problem when a patient tells you that she is not thinking

clearly or is struggling to keep up, or has no time to eat; or is having symptoms of dizziness or sleepiness, or reports to you that “tears flow”, there is a “lack of peace” or that she is “thinking too much”. The majority of this group do not see themselves as having a mental problem and most will expect some sort of medical treatment. On the other hand, when a patient says to you that “she hates herself” or that he has “given up hope” or refers to herself as having “depression” or a “serious mental health problem”, this is unusual, and should alert you to consider that this person could be at risk of coming to harm as a result of a serious problem that is affecting the mind. Another “take home” for caregivers from this study is that many women of child bearing age who present with somatic symptoms are experiencing extreme levels of stress and have been for a long time. Some are being and have been traumatized as a result of poor treatment at the hands of husbands or other family members. These factors take their toll and cause symptoms in the body that are real. Caregivers should become adept at spotting and saying and doing things that are helpful to these individuals. Overall, caregivers should appreciate the importance of trying to understand what the illness means to the patient because what the women in this study told us they want most from the treatment they get from their caregiver is to come away from it feeling better and doing better in life. Receiving a message laced with understanding, encouragement and reassurance may, in some instances, make a big difference and, in every case, it would seem, is their due.

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#### **Compliance with Ethical Standards**

**Conflict of interest** On behalf of all authors, the corresponding author states that there is no conflict of interest.

**Ethical Approval** Ethical approval for this study was obtained from the St Francis Mutolere Hospital in Kisoro, Uganda and from the Institutional Review Board at the University of North Carolina at Chapel Hill. The authors have not misrepresented the research results of this study and have followed all the rules of good scientific practice as outlined under the heading Ethical Responsibilities of Authors in the Instructions for Authors section of the Journal of Culture, Medicine and Psychiatry web-page.

**Informed Consent** Informed consent was obtained from all individual participants included in this study.

**Research Involving in Human and Animal Rights** All procedures involving human participants were in accordance with the ethical standards of the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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## Appendix: Study Instruments

Mental health status was measured by the Self Reporting Questionnaire, 20 items (SRQ 20, WHO 1993; see Table 1),

**Table 1.** Self-Reporting Questionnaire (SRQ 20)

	Yes	No	Don't know
(1) Do you often have headaches?			
(2) Is your appetite poor?			
(3) Do you sleep badly?			
(4) Are you easily frightened?			
(5) Do your hands shake?			
(6) Do you feel nervous, tense or worried?			
(7) Is your digestion poor?			
(8) Do you have trouble thinking clearly?			
(9) Do you feel unhappy?			
(10) Do you cry more than usual?			
(11) Do you find it difficult to enjoy your daily activities?			
(12) Do you find it difficult to make decisions?			
(13) Is your daily work suffering?			
(14) Are you unable to play a useful part in life?			
(15) Have you lost interest in things?			
(16) Do you feel that you are a worthless person?			
(17) Has the thought of ending your life been on your mind?			
(18) Do you feel tired all the time?			
(19) Do you have uncomfortable feelings in your stomach?			
(20) Are you easily tired?			

Source: WHO (1993).

(16) was changed to: ‘Do you feel you that have little worth?’ and (17) was changed to: ‘With all that you have been through, have you thought of ending it all because it is not worth going on?’

### Kleinman’s Eight Questions

Study Participant # \_\_\_\_\_

- (1) What do you call your problem? What name does it have?
- (2) What do you think has caused your problem?
- (3) Why do you think it started when it did?
- (4) What does your sickness do to you? How does it work?
- (5) How severe is it? Will it have a short or long course?
- (6) What do you fear most about your sickness?
- (7) What are the chief problems your sickness has caused for you?
- (8) What kind of treatment do you think you should receive?  
What are the most important results you hope to receive from the treatment?

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