



# Understanding Depression in Rural Chiapas: Contextualizing Quantitative Measures and Patients' Experiences

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UNDERSTANDING DEPRESSION IN RURAL CHIAPAS: CONTEXTUALIZING  
QUANTITATIVE MEASURES AND PATIENTS' EXPERIENCES

JAFET ARRIETA

A Thesis Submitted to the Faculty of

The Harvard Medical School

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**Understanding Depression in Rural Chiapas: Contextualizing Quantitative Measures and Patients' Experiences**

**Abstract**

Depressive disorders are highly prevalent in primary care settings and are associated with severe physical and social impairment. However, it is a challenge for primary health care providers to identify depressive disorders early. The Patient Health Questionnaire-2 (PHQ-2) and PHQ-9 have been widely used for screening and diagnosis of depression in primary care settings.

We used a mixed methods design to assess the validity of the PHQ-9 for diagnosis of depression; to assess the sensitivity and specificity of the PHQ-2 for screening of depression; and to characterize the experience of participants living with depression in rural Spanish-speaking settings. The study was conducted in a rural community of Chiapas, Mexico. Quantitative data was collected using the PHQ-2, the PHQ-9, and the WHO Quality of Life BREF (WHOQOL-BREF) scales during an active case finding activity (n=223). Qualitative data was collected using semi-structured interviews (n=20).

The internal consistency of the PHQ-9 was good (Cronbach's alpha  $\geq 0.8$ ) for the overall PHQ-9 and by subgroups. The PHQ-9 also had good construct validity: participants with a PHQ-9 diagnosis of depression had statistically significantly lower scores on the overall WHOQOL-BREF scale and each of its domains. The optimal PHQ-2 cutpoint score for screening of depression when compared with the PHQ-9 was 3 (sensitivity 80.00%, specificity 86.88%). Four main categories were derived from the qualitative analysis, including life events as triggers for depression; common feelings of sadness and *desesperación*, thinking too much,

and somatization; a experience seeking care influenced by the local conceptualization of depressive illness, the lack of availability of health services, and physicians' failure to recognize symptoms of depressive illness; and a experience of *acompaniment* perceived as therapeutic.

Evidence supports the validity of the PHQ-2 and PHQ-9 to screen and diagnose for depression in rural Spanish-speaking populations, and the association of depression with lower quality of life. The study findings highlight the role of the local context on triggering depression and influencing care-seeking behavior, and on how depressive illness is experienced by patients. Therefore, in order to improve mental health care delivery strategies, strategies and interventions should be adapted to the local context.

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## 1. Introduction

Mental health disorders represent 13.5% of the global burden of disease (Alwan, 2011a). In 2010, mental and substance disorders were the leading cause of disability adjusted life years (DALYs) and years lived with disability (YLD) worldwide, accounting for 37% of all years lived lost (YLL) from non-communicable diseases (NCDs) (Whiteford et al., 2013). Depressive disorders alone accounted for 40.5% of DALYs caused by mental and substance use disorders and represent the most disabling disorder measured in YLDs (Whiteford et al., 2013). In Mexico, mental disorders account for 23% of DALYs for females and 25% for males, of which major depression is the leading cause of disability for female and the second cause for male, accounting for 8.3% and 5.5% of all DALYs respectively (Lozano et al., 2013). The prevalence of major depression has been estimated at 4.4% globally (Ferrari et al., 2013) and at 4.5% in Mexico (Belló, Puentes-Rosas, Medina-Mora, & Lozano, 2005). Major depressive disorders affect mainly young people with a median age of onset ranging from 20 to 25 years in most countries (Andrade et al., 2003), and women are more likely than men to experience them (Andrade et al., 2003; Seedat et al., 2009; Slone et al., 2006).

The recognition of mental health disorders as the leading cause of disability worldwide made evident the need to prioritize mental health in the international agenda (Ferrari et al., 2013; Whiteford et al., 2013). However, lack of access to quality mental health care remains a challenge, particularly in low-income countries where 75% of affected people do not have access to the treatment they need (WHO, 2010). In 2005, in order to address the burden of mental health services, the World Health Organization (WHO) launched the plan “No health without mental health” (WHO, 2005), and the WHO launched the Mental Health Gap Action Programme (mhGAP) in 2008. The mhGAP aims at scaling up services for

mental, neurological and substance use disorders, especially for low and lower-middle income countries. The program asserts that “with proper care, psychosocial assistance and medication, tens of millions could be treated for mental disorders, prevented from suicide and begin to lead normal lives– even where resources are scarce” (WHO, 2010). As part of the program, the WHO launched the mhGAP Intervention Guide with the aim of providing health care providers working at first- and second-level facilities with appropriate tools to facilitate the delivery of evidence-based mental health care interventions in non-specialized settings.

The *Diagnostic and Statistical Manual for Mental Disorders - IV* (DSM-IV) criteria for major depression include depressed mood, loss of interest or pleasure in doing things, low mood, disturbed sleep or appetite, psychomotor agitation or retardation, fatigue or loss of energy, feelings of worthlessness or guilt, diminished concentration, and recurrent thoughts of death or suicidal ideation, suicide attempts or specific plans for committing suicide (American Psychiatric Association, 2000a). Depression not only causes clinically significant distress and preventable suffering, but also causes severe physical and social impairment and lower quality of life (Andriopoulos, Lotti-Lykousa, Pappa, Papadopoulos, & Niakas, 2013; Papakostas et al., 2004; Pyne et al., 1997); and higher health care utilization (Katon et al., 1990; Wu, Erickson, Piette, & Balkrishnan, 2012). However, patients suffering from depression often do not seek help for psychological problems, but instead seek care for somatic symptoms, and their depression often goes unrecognized (Katon & Ciechanowski, 2002; Roness, Mykletun, & Dahl, 2005). It is estimated that for more than half of outpatient medical visits, patients present with physical rather than psychological complaints associated with depression and anxiety (Kroenke, 2003). Furthermore, patients with symptoms of depression often delay seeking care (Benjet,

Borges, Medina-Mora, Fleiz-Bautista, & Zambrano-Ruiz, 2004). Given that patients with depression often delay seeking care and when they do, they seek care for somatic rather than psychological symptoms; it is a challenge for primary health care providers to identify depressive disorders early.

Several screening questionnaires have been developed as tools to guide early detection of cases and clinical decision-making. The Patient Health Questionnaire-2 (PHQ-2) and the Patient Health Questionnaire-9 (PHQ-9) were specifically designed as screening and diagnostic instruments for depression for use in primary care settings (Spitzer, Kroenke, & Williams, 1999). Spanish versions of the PHQ-9 have been reported to be reliable and valid measures of depression in clinical settings in Spain (Diez-Quevedo, Rangil, Sanchez-Planell, Kroenke, & Spitzer, 2001), Honduras (Wulsin, Somoza, & Heck, 2002), Chile (Baader M et al., 2012), and Mexico (Familiar et al., 2015); however, it has not yet been validated in rural and highly marginalized Spanish-speaking settings.

Compañeros En Salud (CES), Partners In Health's sister organization in Mexico, launched a mental health program in 2012 aimed at improving access to quality mental health care in the Sierra of Chiapas, Mexico. As part of the program, CES has been using the PHQ-2 and the PHQ-9 as screening and diagnostic instruments for depression in rural and highly marginalized communities.

The overall aim of this project was to contextualize quantitative measures and patients' experiences living with depression to inform the development and implementation of more comprehensive strategies to effectively deliver care for depression in rural, resource-limited settings. The specific aims of the study were: a) to assess the reliability, and construct validity of

the PHQ-9 for diagnosis of depression; b) to assess the sensitivity and specificity of the PHQ-2 score for screening of depression (if the PHQ-9 proved to be valid); and c) to characterize the experience of participants living with depression in rural Chiapas.

## 2. Data and Methods

### 2.1. Overall approach: mixed methods

We used a convergent parallel mixed methods design to pursue the study aims (Figure 1). In this design, qualitative and quantitative data are prioritized equally and kept independent during data collection and analysis, and then merged and compared during the interpretation to determine convergence or divergence in order to provide a better understanding of the research

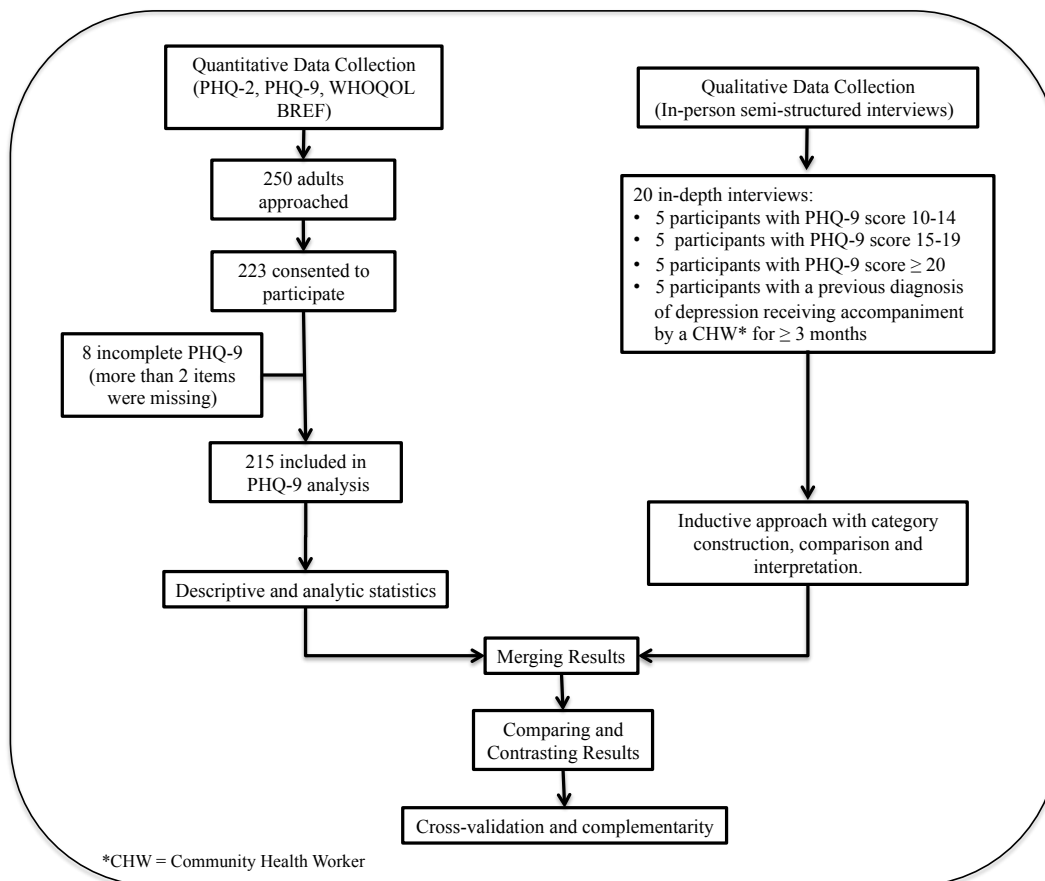


Figure 1. Study Design

question(Creswell & Plano Clark, 2010). The quantitative data was collected using standardized measurement instruments for screening and diagnosis of depression and for assessment of quality of life. The qualitative data was collected using a semi-structured interview guide.

## **2.2.Setting and study population**

### *Overview of Chiapas*

The study was conducted between July and December 2014 in a rural and highly marginalized community of the Sierra Madre Mountains of Chiapas, Mexico in partnership with CES. Chiapas is the poorest state in Mexico and has a population of approximately 5 million (INEGI, 2010). 51.3% of the population lives in rural areas, 30% is indigenous, and 74.6% lives below the poverty line, with 46.7% living in moderate poverty and 27.9% in absolute poverty (INEGI, 2010). In the Sierra, living conditions are difficult, with approximately 30% of homes lacking water, 46% lacking sewage, and 15% lacking electricity (Instituto para el Federalismo y el Desarrollo Municipal, 2010).

### *Access to health care*

In terms of access to health care, Chiapas has the lowest level of effective health coverage which is affected by high levels of marginalization, geographic barriers to access care, poor communication infrastructure and shortage of human resources for health (Lozano et al., 2013). In terms of mental health, the prevalence of depression has been estimated at 6.3% for females and 2.6% for males in Chiapas (Belló et al., 2005). There are only 26 psychiatrists for a rate of 0.54 per 100,000 population (INEGI, 2010), compared to a rate of 2.7 per 100,000 population in Mexico (WHO, 2011).

### *Historical context*

The historical context of the colonization and post-revolution in Chiapas, and of the Sierra Madre region in particular, was characterized by a phenomenon of assimilation and integration of the Mayan-descendant Mam indigenous group into the mainstream Mexican society as peasants, a phenomenon also called “Mexicanization” (Haake, 2007). This phenomenon was endorsed by the federal and local governments, and characterized by struggle and uneasy accommodation between the Mayan population, the Spanish conquerors and the landowners (Womack, 1999). The Mam settled on the Mexican side of the border of Chiapas with Guatemala in the 19<sup>th</sup> century as a result of a colonization process to develop the coffee plantations of the Sierra Madre region (Hernández-Castillo, 2001). The indigenous remained isolated from the national economy developing communities that used a system characterized by agriculture and traditional social organization (Collier, Farias-Campero, Perez, & White, 2000). This process of “Mexicanization” led men and women to experience a historical and cultural rupture characterized by fragmentation and loss of identity, which in turn has contributed to the make and remake of their own identity (Haake, 2007). During this process, women experienced and continue to experience collective and individual gender subordination characterized by culturally violent and harmful practices against them (Hernández-Castillo, 2001).

### *Compañeros En Salud*

CES uses a model of health systems strengthening (WHO, 2007) to revitalize previously under-utilized rural clinics in highly marginalized communities of the Sierra Madre Mountains in partnership with the local Ministry of Health (MoH) and with Mexican and American academic institutions. CES has developed an innovative academic model to recruit social service year

physicians (*pasantes*), who are placed in rural clinics for a year. CES-supported *pasantes* deliver a wide range of services, including care for chronic diseases and mental health disorders. At the time of the study, CES supported the functioning of eight rural clinics covering over 100 rural communities with a direct catchment area of around 18,000 people and approximately 2,200 monthly patient visits.

Recognizing the high burden of mental disorders and the lack of mental health services in the region, CES launched a community-based mental health program (Belkin et al., 2011) aimed at improving access to care and health outcomes. This program consists of active case-finding for depression using the PHQ-2 questionnaire for screening followed by the implementation of the PHQ-9 questionnaire for those who screen positive, who are linked to the clinic for further diagnosis and treatment; adoption and adaptation of clinical guidelines and algorithms for diagnosis and treatment of depression and other mental health disorders; psychoeducation interventions; supply chain strengthening; a robust referral system to specialized care; and *accompaniment* for patients through *accompnateurs*. According to Paul Farmer, “accompaniment is about sticking with a task until it's deemed completed, not by the *accompnateur* but by the person being accompanied (Farmer, 2011).” The accompaniment model is the cornerstone of the work of Partners In Health, and has been widely used by the organization to help patients with tuberculosis, HIV, malnutrition and chronic diseases improve their clinical outcomes. As part of the mental health program, accompaniment is used as a strategy to improve adherence to treatment and health outcomes for mental health disorders, and consists of regular visits to patients by the community health workers (CHWs) to ensure that they are taking their medications, and remind them of their follow-up appointments in the clinic. Health providers and the staff of the mental health team also act as *accompnateurs*.



### **2.3. Ethical approval**

The protocol received ethical approval from the Institutional Review Board (IRB) of the Harvard Medical School Office of Human Research Administration and the Tecnológico de Monterrey School of Medicine IRB. All participants provided verbal informed consent.

### **2.4. Quantitative assessment**

#### **2.4.1. Quantitative measures**

##### *Patient Health Questionnaire-9 (PHQ-9)*

The Patient Health Questionnaire (Appendix 1) was developed to make a criteria-based diagnosis of major depressive disorder. The PHQ-9 consists of 9 items, which evaluate the presence of the 9 DSM-IV criteria for major depressive disorder in the previous 2 weeks. Each item of the PHQ-9 requires a response on a 4-point scale, ranging from 0 (not at all) to 3 (nearly every day), for a total score ranging from 0 to 27, with higher scores indicating higher severity of symptoms and increased likelihood of major depressive disorder (Kroenke, Spitzer, & Williams, 2001). Cutpoints of 5, 10, 15 and 20 represent mild, moderate, moderately severe and severe levels of depressive symptoms respectively (Kroenke, Spitzer, Williams, & Löwe, 2010). A cutpoint of > 9 has been described as diagnostic in systematic reviews of the PHQ-9 (Kroenke et al., 2010), and was used as the cutpoint for the study. If one or two values are missing, they are replaced with the average score of the completed items. Questionnaires with more than two missing values are disregarded (Kroenke et al., 2010). A final question assesses the perception of social, functional and occupational impairment caused by the symptoms examined by the PHQ-9. This last question specifically asks about how difficult the symptoms reported in the PHQ-9 have made for the person to do their work, take care of things at home, or get along with other

people, with 4 possible responses: not difficult at all, somewhat difficult, very difficult, and extremely difficult.

#### *Patient Health Questionnaire-2 (PHQ-2)*

The PHQ-2 consists of the first two questions of the PHQ-9 and evaluates the frequency of depressed mood and little interest or pleasure in doing things over the past two weeks using a 4-point scale ranging from 0 (not at all) to 3 (nearly every day), for a total score ranging from 0 to 6 (Kroenke et al., 2010).

#### *The WHO Quality of Life BREF (WHOQOL-BREF) assessment instrument*

We used the WHOQOL-BREF (Appendix 2) to assess quality of life (QOL). This scale is an abbreviated 26-item version of the WHOQOL-100 containing items that were extracted from the WHOQOL-100 field trial data (Harper, 1996). The WHOQOL-BREF contains one item from each of the 24 facets of QOL included in the WHOQOL-100, plus two items from the general facet on overall QOL and general health. The facets are subsumed in four domains: physical health, psychological health, social relationships and environment. The scores for each of the domains are transformed on a scale from 0 to 20 to enable comparisons to be made between domains composed of unequal numbers of items. A higher score for the WHOQOL-BREF scale reflects a higher level of functioning and quality of life (Harper, 1996).

#### **2.4.2. Quantitative data collection**

Seven medical students conducted a household census as part of a programmatic active case-finding activity and invited all adult residents to participate in the study. Eligible adults were those who were 18 years or older, resided within the study catchment area, and were native

Spanish speakers. The students informed the potential participants about the study and asked for informed consent. After obtaining informed consent, socio-demographic information of the participant was collected followed by implementation of the PHQ-2, the PHQ-9 and the WHOQOL-BREF assessment instrument. Participants with a PHQ-9 score greater than 9 were referred to the clinic to be further screened and diagnosed by the local physician. A trained psychiatrist, blinded to the assessment results, randomly crosschecked 12% of the participants with a PHQ-9 score greater than 9 that were referred to the clinic.

## **2.5. Qualitative assessment**

A subset of 15 participants from the quantitative sample was selected based on their PHQ-9 scores as follows: 5 participants with mild depression (PHQ-9 score: 10-14), 5 participants with moderate depression (PHQ-9 score: 15-19), and 5 participants with severe depression (PHQ-9  $\geq$  20). Five more participants who had been previously diagnosed with depression in the clinic and who had been receiving accompaniment by a community health worker for a period of time equal to or greater than 3 months were purposefully selected to assess their experience with accompaniment. The local physician referred these participants to the Principal Investigator (PI). The PI conducted in-person semi-structured interviews regarding the participants' experience living with and seeking care for depression using an interview guide (Appendix 3). This included questions about their experience seeking care for their symptoms, about the severity of those symptoms including questions on mood, function and cognition, and about their experience living with depression in general. For the 5 participants receiving accompaniment, questions about their experience with accompaniment were added to the interview guide. The interviews were conducted in Spanish. All interviews were audio-recorded and notes were taken. The interviews were then transcribed and translated into English by a

native Spanish-speaker and the PI.

## **2.6.Data analysis**

### **2.6.1. Quantitative analysis**

We excluded from the analysis anyone with more than two missing values in the PHQ-9. To assess internal consistency, we calculated the Cronbach's alpha coefficient of the overall PHQ-9 scores and by subgroups based on gender, literacy and age. We assessed construct validity in two ways. First, we compared WHOQOL-BREF domain scores among people with PHQ-9 scores greater than 9 and less or equal to 9 and tested for differences using Wilcoxon rank-sum test. Based on previous research studies (Andriopoulos et al., 2013; Papakostas et al., 2004; Pyne et al., 1997), we anticipated that the WHOQOL-BREF overall and by domains scores would be lower for those participants with a PHQ-9 score greater than 9. Second, we conducted univariable regression analysis to evaluate the association between socio-demographic data and the PHQ-9 scores. Based on prior studies, we hypothesized that the presence of depression symptoms in this study population would be associated with female gender and with lower socioeconomic status (Andrade et al., 2003; Andriopoulos et al., 2013; Belló et al., 2005; Bromet et al., 2011; Popoola & Adewuya, 2012; Rancans, Vrublevska, Snikere, Koroleva, & Trapencieris, 2014; Slone et al., 2006). Sensitivity, specificity and positive and negative likelihood ratios of the PHQ-2 as a screening instrument were determined by comparing the PHQ-2 scores against the PHQ-9 scores. The receiver operating characteristic curve (ROC) was calculated and used to select the optimal PHQ-2 cutpoint for screening of depression when compared against the PHQ-9 as the gold standard. Statistical significance for all tests was determined at a p-value <0.05. Descriptive and analytic statistics of the quantitative data obtained in this study were computed using STATA 13.1.

### **2.6.2. Qualitative analysis**

An inductive, content-focused approach with category construction, comparison and interpretation was used for data analysis. The text relevant to the research questions was then identified and coded in matrices, including labels, definitions and illustrations with specific examples from the transcripts for each code. Similar codes were grouped into broader categories to characterize participants' experiences and quality of life. Each category was labeled, elaborated and illustrated with excerpts from the data. Categories were then examined interpretively and grouped together linking ideas to a broader concept, from which arguments about the participants' experiences of living with depression were developed. Grounded theory (Yancey Martin & Turner, 1986) and narrative analysis (Clandinin & Connelly, 2000) methodologies were used to conceptualize the qualitative findings. Atlas.ti was used for data coding and management.

### **2.6.3. Mixed methods analysis**

After independently analyzing the quantitative and qualitative data, the PI identified content areas represented in both data sets and merged, compared, contrasted and synthesized the results in a table. The separate results were then interpreted. The researcher assessed to what extent and in what ways the participants' experiences converged, diverged, related or produced a more complete understanding of the PHQ-9 scores.

## **3. Results**

### **3.1. Quantitative findings**

#### *Participant characteristics*

A total of 223 subjects were recruited. 8 were excluded due to incomplete or missing data on the PHQ-9. Table 1 shows the socio-demographic characteristics of the study population. Of the 215 participants, 152 (71%) were female. The mean age of the participants was 38 (SD 16) years and ranged from 18 to 88 years. 21% of the participants were illiterate, 80% of the participants reported having a partner, 86% had children, and 16% did not have access to electricity, water and sanitation. Agriculture was the main economic activity for 90% of the participants. 48% of the participants reported not having enough money for basic expenses, and 44% reported having enough money for food and clothes, but not for other things.

**Table 1. Socio-demographic characteristics of the study population (N=215)\***

Variable	N (%) or mean (SD)
Female gender	152 (71)
Age	38 (16)
Literate	169 (79)
Level of Education	
Secondary or more	69 (32)
Primary or less	122 (57)
None	24 (11)
Has a partner	171 (80)
Has children	185 (86)
Access to services (electricity, water and sanitation)	181 (84)
Water Source	
Tap (inside house)	7 (3)
Tap (in yard)	180 (84)
Communal tap	7 (3)
River/Stream/Pond	21 (10)
Toilet Type	
Flush toilet	6 (3)
Bucket toilet	202 (94)
Pit latrine	1 (0)
None	6 (3)
Energy Source	
Electricity	209 (97)
Wood	5 (2)
None	1 (0)
Economic Activity	
Agriculture	194 (90)
Small business	2 (1)
Both	10 (5)
Other	9 (4)
Religion (N=213)	
Catholic	198 (93)
Presbyterian	6 (3)
Other	5 (2)
None	4 (2)
Financial Situation	
Enough money for food/clothes and other things	16 (7)
Enough money for food/clothes but not other things	95 (44)
Not enough money for basic expenses	103 (48)
Refused to answer	1 (0)

\*Unless otherwise specified

Of the 215 subjects who completed the PHQ-9 questionnaire, 65 participants (30.2%) had a PHQ-9 score equal or greater than 3, and 55 participants (25.6%) had a PHQ-9 score greater than 9. Of the 55 participants with a PHQ-9 score greater than 9, 35 (63.6%) had a PHQ-9 score between 10-14, 13 (23.6%) had a PHQ-9 score between 15-19, and 7 (12.7%) had a PHQ-9 score

greater than 20, corresponding to moderate, moderately severe and severe depression respectively. Of those 55, when asked about how difficult had their symptoms made it for them to do their work, take care of things at home, or get along with other people, 12 (21.8%) referred that it was not difficult at all, 12 (21.8%) referred that it was somewhat difficult, 23 (41.8%) that it was very difficult, 6 (10.9%) that it was extremely difficult, and 2 (3.6%) did not understand the question. Participants with a PHQ-9 score greater than 9 and those who referred self-harm ideation or attempts were referred to the clinic for further screening and diagnosis and were seen by the local physician. Of those 55, 8 (14.5%) had a previous diagnosis of depression and were already receiving treatment at the local clinic, and 35 (63.6%) showed up to their follow-up appointment. Of those 35, 28 (80.0%) were female and 7 (20.0%) were male. Of the participants that showed up, 28 (80.0%) received a confirmatory diagnosis of depression.

A trained psychiatrist, blind to the assessment results, randomly crosschecked 7 (12.73%) out of the 55 participants with a PHQ-9 score greater than 9 who were referred to the clinic through the active case-finding activity. These participants were further evaluated for depression by the psychiatrist using the Hamilton Depression Rating Scale (HDRS) (Hamilton, 1960) and her clinical experience. The psychiatrist confirmed a diagnosis of depression for all 7 participants. Table 2 shows the proportion for each of the PHQ-9 questions and the proportion of participants who did not understand each of the questions. Feeling tired or having little energy with 67.9% of positive answers, followed by feeling down, depressed or hopeless with 55.8% were the most commonly reported symptoms. 25.5% of the study population referred having had thoughts that they would be better off dead or of hurting themselves in some way in the previous two weeks. The questions that were more commonly not understood by the participants were question number 8 (moving or speaking so slowly that other people could have notices, or

feeling so fidgety or restless that you have been moving around a lot more than usual) with a percentage of 6.5, and question number 1 (having little interest or pleasure in doing things) with a percentage of 6.0.

**Table 2. PHQ-9 questions and answer proportion (N=215)**

Questions	Not at all	Several days	More than half the days	Nearly every day	Did not understand
	%	%	%	%	%
1. Little interest or pleasure in doing things	51.6	23.7	6.0	12.6	6.0
2. Feeling down, depressed, or hopeless	44.2	32.1	5.6	17.7	0.5
3. Trouble falling or staying asleep, or sleeping too much	60.0	28.8	1.4	9.3	0.5
4. Feeling tired or having little energy	31.2	38.1	9.3	20.5	0.9
5. Poor appetite or overeating	57.7	26.5	2.8	13.0	0.0
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	55.3	28.8	5.1	8.8	1.9
7. Trouble concentrating on things, such as watching television	61.4	22.3	4.7	8.4	3.3
8. Moving or speaking so slowly that other people could have noticed or being so fidgety or restless that you have been moving around a lot more than usual	63.7	20.0	2.8	7.0	6.5
9. Thoughts that you would be better off dead or of hurting yourself in some way	74.0	16.3	2.8	6.5	0.5

### *Reliability*

The internal consistency of the PHQ-9 was good for the overall PHQ-9 scores and for each of the subgroups evaluated. The Cronbach's alpha coefficient was 0.81 for the overall PHQ-9, 0.85 for males, 0.80 for females, 0.81 for literate participants and 0.83 for illiterate participants; 0.80 for participants younger than 60 years old, and 0.90 for participants 60 years old and older.

### *Construct validity*

Table 3 shows the association between the PHQ-9 scores and the WHOQOL-BREF total score, the physical, psychological, social relationships and environment domains. The median



WHOQOL-BREF score for the overall scale and each of the domains was statistically significantly lower for the participants with a PHQ-9 score greater than 9, except for the social relationships domain ( $p = 0.05$ ).

**Table 3. Association between WHOQOL-BREF domains and PHQ-9 scores**

	PHQ-9<10		PHQ-9>9		p-value*
	N, median (25th, 75th)	N, median (25th, 75th)	N, median (25th, 75th)	N, median (25th, 75th)	
WHOQOL-Physical	152, 16.00 (14.29, 17.14)	51, 12.57 (10.86, 14.87)	51, 12.80 (11.20, 15.33)	53, 16.00 (13.33, 16.00)	<0.0001
WHOQOL-Psychological	151, 16.00 (14.00, 17.33)	51, 12.80 (11.20, 15.33)	53, 16.00 (13.33, 16.00)	53, 16.00 (13.33, 16.00)	<0.0001
WHOQOL-Social Relationships	156, 16.00 (14.67, 17.33)	53, 16.00 (13.33, 16.00)	53, 16.00 (13.33, 16.00)	53, 16.00 (13.33, 16.00)	0.0500
WHOQOL-Environment	147, 14.00 (12.50, 15.50)	51, 13.00 (11.50, 14.29)	51, 13.00 (11.50, 14.29)	51, 13.00 (11.50, 14.29)	0.0007
Total WHOQOL Score	141, 61.24 (57.62, 64.67)	48, 53.77 (46.99, 59.29)	48, 53.77 (46.99, 59.29)	48, 53.77 (46.99, 59.29)	<0.0001

\*Wilcoxon rank sum p-value

The univariable regression analysis (Table 4) showed that having a partner was significantly associated with a 64% reduction in the odds of having a PHQ-9 greater than 9. No other statistically significant association between socio-demographic characteristics and a PHQ-9 score greater than 9 were found. However, although not statistically significant, the direction of the association between the other socio-demographic characteristics and having a PHQ-9 greater than 9 went in the direction that was expected. From Table 4, age, being female, being literate and not having enough money for basic expenses was associated with an increase in the odds of having a PHQ-9 greater than 9; while having children, and having access to services and social programs was associated with a reduction in the odds of having a PHQ-9 greater than 9.

**Table 4. Association between socio-demographic characteristics and PHQ-9 score > 9**

Population (N = 215)		PHQ-9 Score*		
Variable	OR	95% CI	p-value	
Age (per increase in 10 years)	1.01	(0.83, 1.23)	0.920	
Female gender	1.14	(0.58, 2.26)	0.700	
Has a partner	0.36	(0.17, 0.70)	0.003	
Has children	0.54	(0.24, 1.22)	0.138	
Literate	1.54	(0.69, 3.43)	0.290	
Has access to electricity, water and sanitation	0.95	(0.41, 2.18)	0.900	
Not enough money for food/clothes	1.74	(0.94, 3.24)	0.079	
Social programs	0.72	(0.26, 2.00)	0.532	

\*Univariable regression analysis

*Sensitivity and Specificity of the PHQ-2*

Table 5 shows the sensitivity, specificity and positive and negative likelihood ratios of the PHQ-2 for screening of depression.

**Table 5. Sensitivity and specificity of the PHQ-2 for screening of depression**

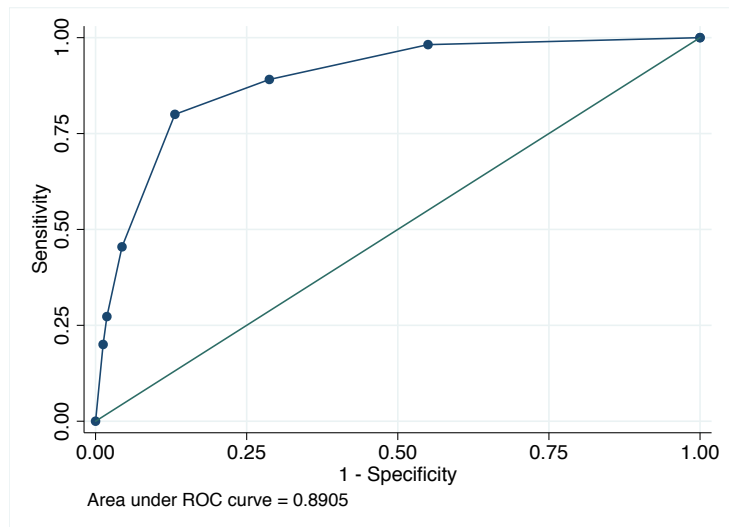
PHQ-2 score	Sensitivity	Specificity	LR+	LR-
≥1	98.18 (54/55)	45.00 (72/160)	1.79	0.04
≥2	89.09 (49/55)	71.25 (114/160)	3.10	0.15
≥3	80.00 (44/55)	86.88 (139/160)	6.10	0.23
≥4	45.45 (25/55)	95.62 (153/160)	10.39	0.57
≥5	27.27 (15/55)	98.12 (157/160)	14.55	0.74
≥6	20.00 (11/55)	98.75 (158/160)	16.00	0.81

The sensitivity and specificity

LR+ = positive likelihood ratio    LR- = negative likelihood ratio

of the PHQ-2 for screening of depression were assessed using the results of the PHQ-9 as the gold standard. The PHQ-2 had a sensitivity of 98.18% and a specificity of 45.00% for a cutpoint of 1 and greater; 89.09% and 71.25% for a cutpoint of 2 and greater; and 80.00% and 86.88% for a cutpoint of 3 and greater, respectively. A cutpoint of 6 or greater had the greatest specificity, with 98.75%. The positive and negative likelihood ratios of the PHQ-2 scores were 1.79 and 0.04 for a cutpoint of 1 and greater; 3.10 and 0.15 for a cutpoint of 2 and greater; and 6.10 and 0.23 for a cutpoint of 3 and greater, respectively.

Compared against the PHQ-9 using ROC analysis, the PHQ-2 performed well in detecting participants with a PHQ-9 diagnosis of depression. The optimal cutpoint for screening of depression was established at a PHQ-2 score of 3 or greater. The area under the



**Figure 2. The Receiving Operating Curve (ROC) of the PHQ-2 for screening of depression**

ROC was 0.89 (95% CI 0.84, 0.94). The ROC is shown in Figure 2.

## **Qualitative findings**

A subset of 15 participants from the quantitative sample was recruited between August and December 2014. 5 more participants who had been previously diagnosed with depression and had been receiving accompaniment for 3 or more months, and who were not part of the quantitative sample, were recruited. Of the 20 participants, 16 (80.0%) were female, 16 (80.0%) were literate, 12 (60.0%) had a partner, and 13 (65.0%) reported not having enough money for basic expenses.

Qualitative results were organized into categories and subcategories, and a case narrative. The categories highlight how participants' attach meaning to, understand and experience depressive illness. The categories correspond to the factors that participants identified as contributing to their depressive illness; participants' experience living with depression in terms of the symptoms of depression that the PHQ-9 assesses; participants' experience seeking care for their symptoms; and participants' experience receiving care and *accompaniment* for their depressive illness. A case narrative using thematic analysis depicts the story of Maria, a 62 year-old female with history of chronic depression, who was found to have a PHQ-9 score greater than 9 during the active case-finding activity, and was purposefully selected to participate in the qualitative part of the study. Maria's case illustrates the categories that had been previously identified and described.

### **Stressful life events as triggers for depression**

When asked about what they think caused their depression, female interviewees identified several stressful events associated with life experiences as depression triggers, including mourning and grief resulting from the loss or separation of a loved one, and episodes

of psychological, physical, and sexual abuse. These episodes of abuse were mainly reported by female participants, who identified their partners as the perpetrators.

### *Mourning and grief*

Participants spoke of how the loss of a close personal relationship, or the death of a loved one, whether it was recent or past, leads to mourning and grief. Mourning and grief are accompanied by feelings of sadness, fear, and hopelessness. Participants identified the separation from and the loss of a personal relationship as triggers for their depressive illness, as illustrated by the following excerpts:

"...I wasn't like this before, I was fine. And now I understand that I started feeling sad when my husband left for the States, that's when I got depressed..." (F, 26)

"I used to be happy all the time before, I had a lot of friends...I was so in love with him [her husband], but we had a problem and that's the reason we split. I thought we would go back together, but he didn't want me back. That's when the sadness started..." (F, 32)

"My husband died six months after my two brothers had died [they died in a car accident]. That's when I started to feel lightheaded. I felt weak. I didn't have strength in my arms. I would get up at 9 in the morning, I would be up for a while, and then I would go to bed again. I would take about 4 naps during the day." (F, 62)

One participant described how the death of her little sister years ago continues to cause her sadness and fear:

"I think it all started when my little sister died, when she drowned and I couldn't save her. I was nine years old, I was in fourth grade. I've been feeling sad and having fears even since. It was not that bad back then. But that's when all started."  
(F, 22)

### *Violence, mistreatment and humiliation*

Female participants identified episodes of physical, psychological and sexual abuse as trigger factors for their depression. They reported these episodes as verbal mistreatment, humiliation, rape, and domestic violence. These episodes of abuse have a negative impact on their self-esteem, their sense of self-worth, their sense of security and their mood, and cause a sense of unfairness among the victims. The following excerpts illustrate:

"My ex partner, I suffered a lot when I was with him. He would beat me. He would humiliate me, mistreat me, and beat me. He would beat me bad. I think that's why I got depressed...I felt bad because he would tell me I was worthless. That I was useless, that I...that I wasn't good at anything. He would tell me: "You are dumb, you are stupid...you are..." He would tell me a lot of things. Sometimes, when he wanted to have sex with me, he would try to force me, and I didn't want. I think that is why I started to feel bad. It was a lot for me...very...How could I say it? ...very, I don't know...maybe that is why I feel depressed and lonely." (F, 30)

"Maybe it was because my husband would used to drink when I first married him, he would force me to have sex with him, even when I told him I didn't want to. I

was very angry with him, I came to hate him because no, no, no. It was horrible every time he would get drunk..." (F, 22)

"He would give me bruises in my legs, my face, my arm, my cheek, everywhere. I would go home with my parents with bruises, all beaten." (F, 58)

One participant described how she found it unfair that the perpetrator continued with his life after sexually abusing her, while she feels like she can't:

"I: What do you think caused your depression? ...It all started when my cousin raped me. I was 9 years old. I was scared of him. I would hide under the bed when he came to visit my grandma, or I would run to my aunt's house. I would always hide, until he left for the States... it's not fair that he can continue with his life and I can't". (F, 24)

### **Experience living with depression**

Depression was associated with physical and psychological symptoms, which often lead to lack of energy, fatigue and little pleasure in doing things. Among the psychological symptoms reported by the participants are feelings of sadness<sup>1</sup> and *desesperación*<sup>2</sup>, and loss of interest in daily activities, changes in sleeping patterns, anger and irritability, and concentration problems. Some of the physical symptoms identified by participants include headaches, aching muscles and bones, stomach pain, loss of energy, lightheadedness, and vomiting. All of these symptoms cause stress among the participants and affect their ability to perform their day-to-day activities.

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<sup>1</sup> Sadness, also called heavy-heartedness, is characterized by feelings of disadvantage, loss, despair,

<sup>2</sup> *Desesperación* refers to the total loss of hope, and is often accompanied by feelings of *coraje* (rage), bitterness and anger.

### *Sadness and desesperación*

Participants characterized depression as sadness and *desesperación*. Concerns about their future and that of their loved ones cause them *desesperación*. Sadness and *desesperación* are often accompanied by stress, crying and suffering. The following excerpts illustrate:

"I felt like my heart tightens. I would feel my heart tighten, and that would make me cry...I would cry, cry and cry. I felt sadness, stress and *desperación* all the time." (F, 48)

"My life has always been sad I tell my daughters, because my first husband was killed, and left me with five children...after my husband was killed, I was suffering, I was suffering for my children. I felt sadness and *desesperación* because I wanted to see my children grow up. "What would they do without me?" I didn't know what to do. I would better cry bitterly. Ay, I couldn't stand it." (F, 45)

### *Thinking too much and insomnia*

Patient participants reported thinking too much while depressed. Thinking too much has been described in the literature as rumination, and has been used to link stress with depression. Rumination suggests a passive and repetitive style of thinking about present and past stressors, negative life events and emotions and loss, and is associated with increased physiological responding, delayed recovery from the stressor, and increased reactivity to a subsequent stress event (Nolen-Hoeksema, 2000; Ruscio et al., 2015).

Participants associate thinking too much with a particular stressor or trigger, such as a family member being chronically ill or lack of social support, as illustrated by the following excerpts:

"...I would think too much, I would think too much about my son's condition [her son had been diagnosed with schizophrenia several years before] and I couldn't sleep, I was just thinking and thinking. One thought would come in, another thought would come out, and then another thought would come in again. Who knows where all of those thoughts came from? I just thought too much."(F, 62)

"After my husband left me, I was always thinking about where I was going to go, where I was going to live...I think I was sad because I would think too much about what to do without the support from my husband." (F, 40)

Thinking too much and not being able to stop those thoughts often led to insomnia for many of the participants. The following excerpts illustrate:

"I'm worried...I'm thinking all the time, before one thought comes out, there is another one coming in, and other one, and other one, and then I just can't fall asleep," (F, 22)

"I go to bed and fall asleep, but then I wake up around 2 am and then I just can't go back to sleep. I stay in bed rolling from one side to the other, thinking.

Thoughts come and go. And then, when I see that it's 4 am, I get up." (F, 30)

### *Depression and somatization*



Physical symptoms and pain often accompany depression and are manifested in a variety of ways. Participants described symptoms that varied idiosyncratically, including headaches, diarrhea, lightheadedness, vomiting, bone pain, stomach pain, fatigue, and weakness. These physical symptoms are often referred to in the literature as “somatization”. The term somatization has been used to describe the dialectic between society and symptoms, and has been described as the expression of personal and social distress in an idiom of bodily complaints and medical help seeking (Kleinman & Kleinman, 1985). The following citation illustrates:

"After my husband died, that's when the vomiting started. I would vomit everyday, everyday, everyday. I felt lightheaded. I felt weak...My feet were sore. My feet and my hands... I didn't have strength in my arms, my legs. I felt weak...I was like that for years, with headaches. My neck would hurt. I felt pain all over my body...I felt like that for years". (F, 62)

These symptoms are often incapacitating, and lead participants to want to be alone and not want to do nothing, as illustrated by the following excerpt:

"I felt lightheaded. I had headaches. I had stomachache. My bones were sore. My feet were sore. I didn't feel like doing anything, not even listen to music, or watch TV. All I wanted was to sleep. I didn't want people to talk to me. I would go to bed, but then when I woke up, I had a headache again, my bones were sore, and my feet would hurt. I was sore all over my body." (F, 45)

### *Depression and mood changes*

Depression causes changes in mood, characterized by anger and irritability. Anger and irritability may lead to violent behavior. Changes in mood negatively affect personal relationships. One participant reported feeling very nervous and emotional, which decreased her level of tolerance and caused her to be violent with her little child. The following excerpt illustrate:

"I don't know. I felt very *desesperada*...I was very nervous, very emotional. Nobody could tell me anything...not even my children. I would beat my little child very often, very often. I was very emotional." (F, 22)

*Tiredness and inability to perform day-to-day activities*

Depressive symptoms such as headaches, lightheadedness, vomiting, diarrhea, and weakness are associated with tiredness and lack of energy. Tiredness and lack of energy impair the ability to perform day-to-day activities and productivity, and impose distress on personal relationships. The following excerpts illustrate:

"I have aches all over my body... I don't want to stand, I don't want to walk, I don't want to talk, I don't want to know nothing, nothing, nothing. I feel really bad...some days my body feels heavy and I don't feel like getting out of bed. I feel like I don't have energy to get out of bed, so I stay in bed...I'm worried... I don't do anything. I don't make my bed, I do nothing. I don't help in the kitchen. So, I tell my mother-in-law [her mother-in-law lives in her house]: "I'm sorry, but I can't help" Sometimes I feel like she gets mad at me because she feels like I'm not taking good care of her son and my children." (F, 22)

“I felt lightheaded. I didn’t want to work. I didn’t work for a year. I didn’t even want to wash my dishes, nothing. I would shiver. I was cold all the time. My son would ask me: “Mother, what is going on? Why are you shivering? It’s hot outside.” Oh, my son, I feel sick, I would tell him. I have chills, I don’t feel like doing anything, nothing...” (F, 62)

"These past weeks I haven't felt like going to work. I feel tired. I go to work, but I don't have energy, I feel tired all the time" (M, 19)

### *Better off dead than alive*

Depression is demoralizing and often makes patients think that they would be better off dead and think of ways of harming themselves. Participants linked these thoughts of self-harm to broader issues, including having lost their sense of purpose in life and feeling like people do not care about them or believing that there is no way out of their problems. The participants elaborated on their ideas of self-harm as follows:

"I felt like nobody cared about me, nobody paid attention to me, nobody would even look at me. And that made me feel bad. That would make me think that I would be better off dead and not alive." (F, 40)

"It makes me sad because I often think that to die is the only option for me, but then I think about my family. That would cause them suffering, but I don't know. I'm very confused. I just can't find a way out." (M, 20)

Interviewees depicted ways in which they have thought of or tried to hurt themselves in the past, which include taking pills or rat poison, and cutting their wrists. Two of the

interviewees referred having ideas of hurting themselves in the present and were linked to care to the clinic:

"I would think a lot about what happened to me. I would feel *desesperada*. That's when I thought that I would be better off dead. It's not easy. I thought about drinking liquid [rat poison], that's what I thought. I would be better off than alive." (F, 26)

"One day I told my husband that if he no longer loved me, that he should tell me because I would disappear of this world, that he would never see me again. I knew what I was going to do. I wanted to kill myself so that he would never see me again. I took a whole bottle of pills. I can't remember which pills, but I took them...They made me sick, I had stomach ache, my stomach was bloated, and then I started vomited. It was horrible, but I didn't die." (F, 26)

"When that happened to me [the participant refused to talk about what had happened to him], that's when I started thinking that I would be better off dead, or about going far away from here...I've always cut myself with a knife or scissors. That helps me feel better, but about 3 years ago I tried to cut my wrists. After that I have tried twice or three times." (M, 19)

### ***Experiences seeking care for depression***

Participants' reports on their experience seeking care for depression highlight the various barriers that exist in terms of both the demand and supply of mental health care. Demand barriers include cultural preferences and participants' conceptualization of the disease, and structural barriers to access health services including costs of access to care and geographical factors.

Supply barriers include lack of availability of health services locally, and doctors' failure to recognize participants' symptoms as part of a disease.

*Susto, espanto, and coraje and: Local idioms of distress and care-seeking behavior*

Local context, culture and belief systems influence the way in which people conceptualize and experience depressive illness. The conceptualization of disease influences the decision to seek care for illness manifestations of depression. Participants used local idioms of distress to characterize their conceptualization of depression. *Susto*<sup>3</sup> (*frighten*), *espanto*<sup>4</sup> (*the reaction to a fright*) and *coraje* (*rage*) were used by the participants as local idioms of distress, and were associated with *desesperación*, and somatic symptoms of depression. The following excerpt illustrate:

"I didn't seek care before because I didn't think that what I had [the fear, the *desesperación*, my nervousness] was a disease." (F, 22)

"A snake had coiled in my foot, and my mom says that maybe that was the cause of my *susto*, of my *desesperación*. That caused me the *espanto*...but I have already been cured from the *espanto*. My mom took me to a person that knows how to cure the *espanto*." (F, 32)

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<sup>3</sup> *Susto* refers to a fearful response to experiencing or witnessing a threatening event or in relation to a loss. Its symptoms include weakness, somnolence, and loss of appetite, fever, diarrhea, depressed mood, and hesitancy. *Susto* and *espanto* are used in the literature interchangeably.

<sup>4</sup> *Espanto* is an illness that usually originates when someone receives a sudden fright and is terrified. It is also called "*la pérdida de la sombra*" or "loss of the shadow" meaning that a person's shadow, symbolizing his or her soul, has separated from their body. It is said that the person suffers from "tired blood." *Susto* and *espanto* are used in the literature interchangeably.

"...[*coraje*] is what makes you sick. One doesn't get sick just because, it happens because someone throws a *coraje* towards you. So, one day I found myself very sick. That's when my family took me to see a doctor. I had a headache and pain everywhere. I thought I was going to die." (F, 45)

Participants reported seeking care with traditional healers when experiencing symptoms of depression, especially when those symptoms were psychological, as illustrated by the following excerpt:

" I would cry and cry, I had a lot of stress, *desesperación* and sadness...That's when my husband decided to take me to see a lady in a community nearby. She prescribed me a tea of 3 leaves of lime, 3 leaves of basil, and 3 leaves of peppermint for 6 months. I took it for 2 months and I started feeling better. But then I stopped it." (F, 48)

#### *Lack of availability of mental health services, geographic barriers and cost of access to care*

Lack of access to mental health care is determined in part by lack of availability of health services in general, which leads to individuals having to travel outside of their communities to seek medical care. Participants spoke of some of the barriers they face to access care for depression. These barriers include having to travel to different places, some times for very long hours and distances to seek care; and having to pay out-of-pocket for access to care, which caused further stress to the participants. Among those who were able to travel outside of their community to a health care center, some were still unable to consult with a doctor because of the high demand for services. The following excerpts illustrate:

"It would take me 12 hours to get to Guatemala, where I went to see a doctor. We would leave at 4 in the morning." (F, 65)

"I've gone to a lot of places, and I see patients get there at 4am...and there's a lot of people, so they tell me that they can't see me, that there is no time." (F, 29)

"We spent a lot of money, sometimes 2,000, or 1,800, or 500 pesos [130, or 120, or 30 USD]. We spent a lot of money; my husband spent a lot of money with me. And nothing, nothing, nothing. Sometimes I cry because my husband is spending a lot of money in me, money that we don't have." (F, 22)

#### *Physicians' failure to recognize depression*

Participants spoke of their experience seeking medical care for psychological and physical symptoms. Doctors often were not able to recognize participants' symptoms as depression. Doctors' inability to recognize depression discouraged participants to continue to seek care for their symptoms. The following excerpt illustrates how a participant decided to stop seeking care for her symptoms after a doctor told her that there was nothing wrong with her that it was all in her mind:

"I started feeling like this a long time ago. I went to see other doctors. My daughters would take me to the clinic, and the doctor would examine me, and then he would tell me: "There is nothing wrong with you". And that's why I decided to stop going. I didn't feel like going [to see a doctor] again. I didn't feel well, my body hurt and it made me feel bad that they said that I was fine, that all was in my mind." (F, 45)

### *Experience with accompaniment*

Accompaniment provided by caregivers, which included family members; friends and health providers helped patients to feel noticed and cared for. Feeling noticed and cared for made participants feel happy and gave them the hope that they would get better. Feeling happy helps participants continue to do and enjoy their day-to-day activities and improves their personal relationships.

### *The therapeutic relationship*

Positive relationships with health care providers were considered to be therapeutic by the participants. Participants spoke of how receiving accompaniment from health care providers, including medical students, doctors and community health workers has made them feel happy and better, and of how feeling happy and better has had an effect on their ability to participate in their day-to-day activities. The following excerpts illustrate:

"They [the community health workers] know us, at least I know the one who visits me. She is very close to my family and knows what I am going through. She understands me and asks me how I am doing. She visits me all the time". (F, 20)

"She has helped me a lot [the community health worker], because when I was alone she would come visit me. When she visits me, we talk. And since I know her, and trust her, I tell her about my problems and she helps me...I am very happy with her." (F, 40)

"I don't feel like that [sad] anymore. I feel happy, happy because now I can do my day-to-day activities, wash the clothes, make tortillas, and take care of my partner. I thank you and your colleague [a mental health program member] for visiting me,



because it was because of him that I feel better now...to me, he was like a genie. He made me think of what was happening to me. He would talk to me, and help me with my problems, and that filled me with the hope that I would get better [*salir adelante*]...If I hadn't gone to the clinic, if it hadn't been for him, I would still be sad, but now I am happy...I feel so happy now that other people notice it and congratulate me." (F, 40)

### **The case of Maria**

Maria<sup>5</sup> was one of the first patients to get a diagnosis of depression in El Lago<sup>6</sup>, a rural and highly marginalized community of Chiapas. El Lago is located in the Sierra Madre Mountains of Chiapas, and has a population of fewer than two thousand people. El Lago is a community of peasants, peasants who used to be indigenous, but who had to abandon their cultural traditions and language after a process of “Mexicanization” that took place in Chiapas after in the 1940s. The roads to El Lago are bumpy and dusty during the dry season, and muddy during the rainy season, making them dangerous to navigate. Travel time from the takes long hours and car accidents are common. It takes up to 8 hours to get to the community from Tuxtla Gutierrez - the capital of Chiapas – during the rainy season. People in El Lago were forced up from the valleys into the mountains by the Chiapanecan squirearchy, where they would become farmers and grow coffee, corn and beans mainly.

People from El Lago lacked access to health care until 2012 when CES placed a social service year physician in the community clinic. Maria was one of the first patients in El Lago to

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<sup>5</sup> The patient’s name has been changed to protect her real identity. Certain additional details have also been changed to assure anonymity and confidentiality.

<sup>6</sup> The name of the community has been changed to assure anonymity and confidentiality.

be diagnosed with depression, but her illness had started to manifest decades ago, and was only one of the many tragedies that her family had suffered from.

Maria is 62 years old. She is a widow. She had to drop out of primary school to start working to support her family. She got married when she was 20 years old, and had 7 children. She and her family live on the top of the hill, the most difficult-to-access neighborhood of the community. They lacked access to electricity until several years ago.

Maria's story with mental illness begins when she was 27 years old, following the death of two of her siblings in a car accident, which was in turn followed by the death of her husband from a bleeding gastric ulcer six months later. After her husband and two siblings died, Maria found herself without family support and being responsible for providing for all her 7 children. Years later, two of her children got sick with convulsions and, according to Maria, one of them – Ramon-, went “crazy” when he turned 14 years old. Ramon would lock himself in his room and wouldn't eat or talk to anyone for days. That's when he started talking to himself, laughing and crying without any evident reason; he was scared; he would cover himself with his blanket so that people wouldn't look at him, because he was ashamed of his big, “donkey-like” ears, Maria recalls. Maria thought Ramon had been cursed or bewitched, and started seeking care for him with traditional healers, witches, shamans and physicians in different places of Chiapas and Guatemala. In Guatemala, Maria was told that Ramon had a tumor in his head and needed a surgery. Maria took him to Tuxtla Gutierrez –the capital of Chiapas- to another doctor, where she was told that he didn't have a tumor, that he was fine. Then, Maria and her oldest daughter took Ramon to a witch in Tuxtla Gutierrez, who told them he had been bewitched. He gave them a bible and asked them to pray “Our Father” and the “Hail Mary” prayers 7 times every day, and

gave them an herbal tea remedy for him to drink. They took him to see the witch every week for a year. Ramon did not improve.

When asked about what she thought was the cause of her depression, she identified the death of her siblings and husband decades ago, her children being sick, and the need to provide for them as triggers for her depressive illness, which manifested with sadness and *desesperación*, thinking too much and insomnia, inability to perform her day-to-day activities, tiredness, and a wide variety of physical symptoms. "... I felt weak. I didn't have strength in my arms. I would get up at 9 in the morning, I would be up for a while, and then I would go to bed again. I would take about 4 naps during the day... I felt like that for years, I had headaches. My neck would hurt, everything would hurt, and my legs would hurt. I felt weak. I would go to sleep. And I had vomiting, I would vomit all the time," she reported.

When Ramon turned 20 years old, he started getting very aggressive towards Maria, his siblings, his nephews and nieces, and whoever would get close to him. He would use wood sticks, belts and rocks to hurt them. "...One day Ramon got home and threw a rock at his brother; Maria's brother in law tried to help, but Ramon took off his belt and started hitting him with it, then threw him to the floor and started biting him and scratching him...we were afraid of him...we all suffered a lot with him..." Maria recalls. Ramon would threaten his them with

Maria recalls how she continued navigating the system seeking care for her son and for herself, having to travel long distances and spending large amounts of money. Doctors would tell her that she was fine, that all she had was stress. After seeking care for her son for years with multiple traditional healers, charlatans and doctors, Ramon was finally diagnosed with schizophrenia and was started on ambulatory medical treatment. His treatment, however, cost her

3,800 Mexican pesos (250 USD) per month, which was more money than what Maria would earn in 3 months. In order to be able to pay for Ramon's treatment, Maria had to move to the Tuxtla Gutierrez to work leaving her other children behind. She also had to borrow money from family and friends. Unable to afford Ramon's treatment despite all her efforts, Maria decided to move back to the community and stop buying his medications. Ramon became even more violent and often times would leave the community for days without Maria and her family knowing where he was. He would get into trouble and be arrested multiple times. Maria and her family decided to chain him as a way to protect him and themselves from his violent behavior and from running away.

Maria reported how much Ramon's situation affected her physically and emotionally. "I felt lightheaded. I didn't want to work. I didn't work for a year. I didn't even want to wash my dishes, nothing. I would shiver. I was cold all the time. My son would ask me: "Mother, what is going on? Why are you shivering? It's hot outside." Oh, my son, I feel sick, I would tell him. I have chills; I don't feel like doing anything, anything...I would think too much about Ramon's situation. I couldn't sleep. I was just thinking, and thinking. One thought would come in, another would come out. Who knows where all of those thoughts were coming from?" she remarked. Maria was suffering not only from her own illness, but also from seeing her son suffer, and from being poor and not being able to provide for her children. Her suffering made her think that she would be better off dead. "If I just died, I would think. If I just died so that I wouldn't think too much, so that I would suffer so much. I was poor and my children were sick. They were sick and I was sick. I needed money, but where would I get it? Nobody would give us even 5 pesos (less than 50 USD cents)," she mentioned.

Over two years ago, when Maria found out that there was a new doctor in the community, she went to see him, explained him Ramon's situation and asked him if he could go see him to her house. The doctor diagnosed her with depression, and visited Ramon later that week. They were both started on treatment. Ramon started to show significant clinical improvement and was unchained several months later. He now helps his brother in his family's coffee field. Maria reported how Ramon's clinical improvement helped her feel better from her physical and psychological symptoms. At the time of the interview, Maria was under medical treatment for depression at the local CES-run clinic, and had been receiving a psychoeducation intervention for about a year. Although she still feels sad and *desesperada* from time to time, she reported having started to recover the weight she had lost, sleeping better, and enjoying her day-to-day activities. She mentioned that even other people have told her that she looks better, happy. "The other day, a boy that came from a nearby community and that I hadn't seen in years looked at me and told me: "Ms. Maria, last time I saw you, you were very thin, but now you look fat, you look younger, you look happier",," she reported.

Maria referred being satisfied and happy with the care that she had been receiving at the local clinic and with all the members of the mental health team. "The first doctor that came with CES is the one who helped us. It was as if he had pulled us out of a quagmire. When he left, I cried, I was very grateful because no other doctor had helped us before, he gave us the medications for my son and myself," she mentioned.

Maria's case highlighted the role that stressful life events such as mourning, grief and violence play in triggering depression; the way in which depressive illness affects physical and psychological health and social relations; the experience seeking care for depression, including the structural barriers and challenges faced by patients and their families to access care and the

way in which the local conceptualizations of depressive illness relate to care seeking behavior; and doctors' failure to recognize depression. This case also disclosed the role of families and health care providers in the therapeutic process.

### 3.2. Merging qualitative and quantitative findings

In this section, quantitative and qualitative results are merged. Content areas represented

Table 6. Crossvalidation of the PHQ-9 scores by level of symptom severity and participants' experiences

PHQ-9 category	Mood	Function	Cognition	Self-harm thoughts and attempts
10--14	"I was very desesperada. First, I was nervous, but I didn't feel that desesperación. The desesperación started later. I don't know. I felt very desesperada...I was very nervous, very emotional. Nobody could tell me anything...not even my children. I would beat my little child very often, very often. I was very emotional."	"I have aches all over my body... I don't want to stand, I don't want to walk, I don't want to talk, I don't want to know nothing, nothing, nothing. I feel really bad... Some days my body feels heavy and I don't feel like getting out of bed. I feel like I don't have energy to get out of bed, so I stay in bed...I'm worried... I don't do anything. I don't make my bed, I do nothing. I don't help in the kitchen."	"In school, I wasn't able to concentrate in classes. I didn't even listen to the professor."	"It makes me sad because I often think that to die is the only option for me, but then I think about my family. That would cause the suffering, but I don't know. I'm very confused. I just can't find a way out."
15--19	"I feel sad and bored. I feel better when I'm around other people, or when I'm with my dad, because I can talk to him, and I no longer feel bored."	"I always wake up in the middle of the night, at least twice. I usually go to bed around 10 pm, but I wake up around 1 am and I really struggle to fall asleep again. And then in the morning I don't want to get out of bed, but I have to get up at 5 am to go to work with my dad... I feel tired. I go to work, but I don't have energy, I feel tired all the time."	"When I am all <i>desesperada</i> I forget what I'm doing. One day I forgot to pick my little child from school."	"When that happened to me [the participant refused to talk about what had happened to him], that's when I started thinking that I would be better off dead, or about going far away from here...I've always cut myself with a knife or scissors. That helps me feel better, but about 3 years ago I tried to cut my veins. After that I have tried twice or three times."
20--27	"I felt like my heart tightens. I would feel my heart thingthen, and that would make me cry...I would cry, cry and cry. I felt sadness, stress and <i>desperación</i> all the time."	"I have headaches every night, sometimes also in the mornings. Now that the doctor told me that I have depression, I think maybe the headaches have to do with that."	"...I would think too much, I would think too much about my son's condition [her son had been diagnosed with schizophrenia several years before] and I couldn't sleep, I was just thinking and thinking. One thought would come in, another thought would come out, and then another thought would come in again. Who knows where all of those thoughts came from? I just thought too much."	"One day I told my husband that if he no longer loved me, that he should tell me because I would disappear of this world, that he would never see me again. I knew what I was going to do. I wanted to kill myself so that he would never see me again. I took a whole bottle of pills. I can't remember which pills, but I took them...They made me sick, I had stomach ache, my stomach was bloated, and then I started vomited. It was horrible, but I didn't die."

in both data sets are identified, compared and contrasted. Table 6 displays the quantitative PHQ-9 scores categorized by symptom severity and the qualitative findings that correspond to participants within those categories. The qualitative findings corresponded with the quantitative scores for the four dimensions (mood, function, cognition, and referred thoughts and attempts of self-harm) that are concurrently examined in both datasets, and are illustrated by excerpts from the qualitative interviews.

When merging the results, the qualitative findings provided more detail about the symptoms related to mood, cognition, functioning and thoughts of self-harm. As the score of the PHQ-9 increased, we observed that participants' reported experiences in all four domains were more severe and incapacitating. While the quantitative score reflected the severity and frequency of the symptoms, the qualitative findings expanded more on the experience of living with these symptoms not only in terms of severity and frequency, but also in terms of intensity. The qualitative findings expand on and complement the quantitative findings.

#### **4. Discussion**

This mixed methods study examined the validity of the PHQ-2 and the PHQ-9 as screening and diagnostic instruments for depression; to examine the quality of life and experience living with and seeking care for depression; and the concordance between the PHQ-9 scores and participants' reported experiences in rural Chiapas. This study is the first report of the validity of screening and diagnostic instruments and of measured quality of life and the first report to use qualitative data to contextualize quantitative measures for depression in rural Spanish-speaking populations.

*Validity and utility of quantitative measures for screening and diagnosis of depression*

The quantitative data provided strong evidence for the validity and reliability of the PHQ-9 questionnaire as a diagnostic tool for depression. The internal consistency measured by the Cronbach's alpha was found to be adequate for the overall PHQ-9 and by subgroups. Construct validity was supported by the statistically significant association between PHQ-9 scores and overall WHOQOL-BREF scores, and each of its domains, where a PHQ-9 score greater than 9 was associated with lower quality of life. This association was consistent with previous studies from primary care settings (Andriopoulos et al., 2013; Brenes, 2007; Papakostas et al., 2004; Pyne et al., 1997). Also, the results supporting the validity of PHQ-9 were similar to those seen in other studies from primary care settings (Adewuya, Ola, & Afolabi, 2006; Andriopoulos et al., 2013; Baader M et al., 2012; Kroenke et al., 2001; Martin, Rief, Klaiberg, & Braehler, 2006; Shin et al., 2010; Spitzer et al., 1999), which enhance the generalizability of our findings. In the study population, having a partner was statistically associated with a reduction in the odds of having a PHQ-9 score greater than 9. This finding was consistent with previous reports in the literature (Andrade et al., 2003; Bromet et al., 2011; Slone et al., 2006). Also, although not statistically significant, being female, being literate and not having enough money for basic expenses were also associated with an increase in the odds of having a PHQ-9 greater than 9; while having children, and having access to services and social programs was associated with a reduction in the odds of having a PHQ-9 greater than 9. The association between being female and having a PHQ-9 score greater than 9 is consistent with the results from previous studies (Andrade et al., 2003; Belló et al., 2005; Liu et al., 2015; Rancans et al., 2014; Seedat et al., 2009; Slone et al., 2006; Woodward et al., 2012). Contrary to the findings from earlier studies from urban settings in Mexico that have found an association between higher educational level with



lower prevalence of depression, the results of our study showed that being literate was associated with having a PHQ-9 greater than 9 (Belló et al., 2005; Bromet et al., 2011; Slone et al., 2006). The association between literacy and depression in rural, resource-limited settings should be further studied.

Brief tools are needed to effectively screen patients for depression in primary care settings where demand for services is high and health professionals are scarce (Kroenke, 1997; Williams, 1998). In this study, the PHQ-2 and PHQ-9 questionnaires were implemented in the context of an active case-finding activity for depression. Our study provides strong evidence for the validity of the PHQ-2 as a brief tool to screen for depression. The PHQ-2 showed high sensitivity and specificity as a screening instrument for a diagnosis of major depression when compared with the PHQ-9. A cutpoint of 3 and greater was optimal for the study population given both its high sensitivity (80.00%) and specificity (86.88%). However, selecting an optimal PHQ-2 cutpoint should be done cautiously in order not to compromise a lower sensitivity for a higher specificity. The sensitivity and specificity of the PHQ-2 in the study population were similar to previous studies in the literature from primary care populations (Arroll et al., 2010; Kroenke, Spitzer, & Williams, 2003; Richardson et al., 2010). The positive likelihood ratio increased as the cutpoint increased and was of 6.10 for a cutpoint of 3 or greater, which means that having a PHQ-2 score of 3 or greater is 6.10 times more likely among those with a PHQ-9 score greater than 9. The positive and negative likelihood ratios are a combination of sensitivity and specificity and are useful for clinicians especially in settings like ours where the true prevalence of depression is unknown (Arroll et al., 2010).

*Mourning, violence, abuse and loss as triggers for depression*

Participants' experiences highlighted the role of stressful life events such as the separation or loss of a loved one, rupture of social relations, and episodes of psychological, physical and sexual abuse on triggering depression. Participants spoke of the negative effects of abuse and violence on their self-esteem, sense of self-worth and sense of security. The diathesis–stress model asserts that the presence of a stressor in people with an existing diathesis or predisposition has the potential of triggering depression. This model asserts that if the combination of the predisposition and the stress exceeds a threshold, the person will develop the illness (Ingram & Luxton, 2005). This model is useful to better understand the role of stress derived from life events on triggering depression in this setting. Several participants spoke of how the loss or separation of a loved one and the mourning and grief that came with it was the cause of their depression. Attachment theory speculates that the rupture in an individual's intimate attachments make vulnerable individuals more likely to suffer psychological distress (Levy & Orlans, 2014). In the Mayan culture, illness has been interpreted as resulting from rupture and transgression in social relationships; where the transgressor may suffer divine punishment, but the wronged person may suffer illness resulting from, for example, *coraje* or *susto* (Collier et al., 2000). Mayan people have historically experienced cultural ruptures that have led to the loss and remake of their identity (Haake, 2007). In this culture, women have historically been victims of gender subordination, oppressive social relations and violence (Hernández-Castillo, 2001). According to a study on violence against women in community settings in Mexico, 17.8% of women in Chiapas suffer from some type of violence every year (INEGI, 2011). These findings highlight the social burden of depression, and the need for targeted interventions to prevent physical, psychological and sexual violence against women in these settings. A full discussion of this issue is beyond the scope of our study.

### *Local conceptualizations, psychological symptoms and somatization of depressive illness*

The conceptualization and subjective experience of depressive illness among the participants was shaped by the local context and by the culture and belief systems of individuals, and was expressed using local idioms of distress. Some of the local idioms of distress identified were *susto or espanto, desesperación and coraje*, some of which were attributed to ruptures in social relationships or to some type of sorcery. People in the developing world often attribute psychiatric illness to social, religious and supernatural events (Castro & Eroza, 1998). The existence of *susto*, also known as *espanto*, has been documented in Latin America (Rubel, O'Neill, & Collado-Ardon, 1984) and Mexico (Gillin, 1945; Mendenhall, Fernandez, Adler, & Jacobs, 2012) before. It refers to a fearful response to experiencing or witnessing a threatening event or in relation to a material, personal, physical or moral loss, often associated to grief, and its symptoms include weakness, somnolence, loss of appetite, fever, diarrhea, depressed mood, and hesitancy (Castro & Eroza, 1998). Furthermore, depressive illness among the participants was associated with the presence of psychological symptoms such as sadness and *desesperación*, and with thinking too much and multiple somatic and unspecific symptoms, which affected the ability of the participants to perform their day-to-day activities. The somatic symptoms of depressive illness included headache, diarrhea, lightheadedness, vomiting, bone pain, stomach pain, fatigue, and weakness. Somatization is characterized by bodily complaints that express personal and social distress (Kleinman & Kleinman, 1985). Cultural experiences and narrative analysis have been linked to explain the meaning and experience of pain within specific cultures (Good, Brodwin, Good, & Kleinman, 1992). According to Kleinman, “illness narratives tell us about the way cultural values and social relations shape how we

perceive and monitor our bodies, label and categorize bodily symptoms, and interpret complaints in the particular context of our life situation. We express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition.” (Kleinman, 1988) However, in the cross-cultural study of mental illness, the symptoms and causes do not map across cultures (Collier et al., 2000); therefore, it is fundamental to pay attention to the local cultural environment to understand the meaning and experience of illness (Kleinman & Good, 1985), and to take into consideration the relationship between physical and psychological symptoms when designing strategies to deliver mental health care. These findings highlight how depressive illness has been socially constructed in this setting, and how this construct has been integrated into socially and culturally legitimated ideas and practices(Kleinman, 2010).

#### *Thoughts of being better off dead than alive*

A high proportion of participants reported having had thoughts that they would be better off dead or of hurting themselves in some way in the previous two weeks in the PHQ-9. While the PHQ-9 was able to capture the presence and frequency of thoughts of being better off dead than alive and of self-harm, it did not capture the intensity of those thoughts nor did it capture attempts prior to two weeks. However, the qualitative findings complemented the results from the PHQ-9 and reflected the depth of those thoughts, which were linked to having lost the sense of purpose in life and believing that there is no other way out of their problems. Some of the most common ways in which the participants have tried to hurt themselves included drinking rat poison, taking pills, and cutting their wrists. The triggers for attempting to commit suicide were often associated with personal disputes and violence. Given that reports of having thoughts of self-harm were common, further studies should be conducted to assess the association of these

thoughts with social, economic and health factors in order to develop strategies aimed at preventing suicide in these settings.

#### *Perceived social, functional and occupational impairment*

When asked about their perception of social, functional and occupational impairment caused by the symptoms examined by the PHQ-9, more than half of the participants with a PHQ-9 diagnosis of depression referred that it was very difficult and extremely difficult for them to do their work, take care of things at home, and get along with other people. These results were consistent with lower scores for the social relations and environment quality of life WHOQOL-BREF domains among participants with a PHQ-9 diagnosis of depression. The qualitative data allowed for a better understanding of the perceived social, functional and occupational impairment caused by depression. Participants reported that their somatic symptoms are often incapacitating and affect their ability to do their day-to-day activities, such as working in their coffee farms for males, and cleaning the house and taking care of their spouses and children for females. They also spoke of how their inability to do their day-to-day activities and the presence of psychological symptoms of depressive illness affect their social relationships with their spouses, their children and their friends. Pain and suffering caused by depression are, therefore, not limited to the individual, but that they also affect the family and individual's social network, as asserted by the social suffering social theory (Kleinman, 2010). Systematic efforts towards describing, documenting and characterizing the social suffering associated to depression in these settings should be taken as a way of raising awareness about the social burden of depression.

#### *Care seeking experience: Supply and demand side barriers*

The qualitative findings describe some of the supply and demand barriers to seek and receive care in this study setting. The supply side barriers that were identified included lack of availability of health services locally and doctors' failure to recognize participants' symptoms as part of a depressive illness. Given the lack of availability of services locally, participants referred having had to travel out of the communities to seek care, and having sought care with private doctors given that the waiting times in public clinics were long. Previous studies have documented the barriers to seek care for depression (Benjet et al., 2004; Familiar et al., 2013; Jesse, Dolbier, & Blanchard, 2008; Roness et al., 2005; WHO, 2011). Lack of access to mental health care has been documented in the literature as one of the major factors contributing to care seeking delays for depression in resource-limited settings (WHO, 2011). In Mexico, the delay to seek treatment has been reported at 10.6 years for early-onset depression, and 1.8 years for late-onset depression, on average, and has been attributed to the lack of early detection and of timely treatment of depression (Benjet et al., 2004). In rural areas, this lack of access is conditioned by the shortage of mental health professionals, medications and infrastructure (Kitchen Andren et al., 2013).

Participants' experiences seeking medical care for their somatic symptoms of their depressive illness were characterized by the inability of physicians to recognize their symptoms. This inability to recognize somatic symptoms as part of a depressive illness often led doctors to focus on the somatic complaints and to treat them as if they existed in isolation. Participants' were often told that they were "fine" and that they had "nothing", that it was all in their minds, which either discouraged them to further seek medical care or made them go see multiple physicians with the hope that they would be able to find a cure for their illness. Doctors are traditionally trained to recognize the psychological symptoms of depression, which have to meet

the DSM criteria based on clinical symptoms to be granted a diagnosis of depression (Katon et al., 1990). However, in these settings, patients' often seek medical care only for somatic symptoms rather than for psychological symptoms. The fact that the symptoms are unspecific and common to other diseases, and that the criteria do not consider the cultural and social context or circumstances under which these symptoms present, make it easier for physicians to mistake depression for other diseases. The inability of physicians to recognize depression when patients present with somatic symptoms rather than psychological symptoms has been documented in previous studies from primary care settings (Katon & Ciechanowski, 2002; Roness et al., 2005). In the WHO Psychological Problems in General Health Care study, the physicians correctly recognized depression in only 42% of patients attending a primary care consultation for depressive symptoms (Simon, Goldberg, Tiemens, & Ustun, 1999). Therefore, to address some of the supply side barriers to care, it is imperative not only to improve access to mental health care in these settings, but also for primary care providers to be aware of the way in which depressive illness is conceptualized and manifest in these settings and of the common depressive somatic symptoms for which they seek care.

Demand side barriers included cultural preferences and participants' conceptualization of the disease, geographic and financial barriers. Participants referred seeking care for psychological symptoms that they attributed to natural events of life or supernatural factors with traditional healers, and it was only for somatic symptoms that they referred seeking care with allopathic physicians. In Mexico, traditional medicine has, historically and culturally, played a major role in health care, and continues to be widely used in rural areas and among underserved and indigenous populations (Nigenda, Mora-Flores, Aldama-Lopez, & Orozco-Nunez, 2001; Pedersen & Baruffati, 1985). There is a notion that traditional medicine integrates the

emotional, physical, mental, and spiritual aspects of the being (Dime, 1995). In Chiapas, traditional medicine has traditionally been practiced by local traditional healers, who, as insiders and long-term members of the communities, are thought to better understand patients' beliefs and values.

Participants spoke of the geographical and financial barriers to access care for depression. They reported having had to travel out of their communities for long hours and having had to pay out-of-pocket to receive care, causing a high financial burden for the study participants and their families given that most of them referred not even having enough money to cover for basic expenses. These barriers not only contribute to care seeking delays and prevent people from receiving timely care, but also condition them to suffer from the social, functional and occupational impairment that depression causes. Beyond the individual-level and medical paradigms conditioning the delays in seeking care from the demand and supply side, there exist social, political and economic forces driving the risk of developing mental illnesses, which disproportionately affect the most vulnerable groups within and across communities (Farmer, 2003).

#### *The therapeutic effect of accompaniment*

The perceived therapeutic effect of accompaniment on depression emerged from the qualitative findings. Participants' experience receiving *accompaniment* from health providers and community health workers showed a positive effect on their sense of wellbeing and their process of recovery. "She has helped me a lot [the community health worker], because when I was alone she would come visit me. When she visits me, we talk. And since I know her, and trust her, I tell her about my problems and she helps me...I am very happy with her," referred



one of the participants. This excerpt highlights the notion that “to accompany someone is to go somewhere with him or her, to break bread together, to be present on a journey with a beginning and an end. There's an element of mystery, of openness, of trust, in accompaniment. The companion, the *accompagnateur*, says: "I'll go with you and support you on your journey wherever it leads; I'll share your fate for a while. And by 'a while,' I don't mean a little while.” (Farmer, 2011) However, as Farmer argues, accompaniment is about more than walking. It requires not only recognizing and understanding the complexities and challenges of the real world in which individuals live and the asymmetries of power that condition them, but also being willing to address them “*while walking together.*” (Farmer & Gutierrez, 2013)

*Accompaniment* in this setting was also closely related to the concept of caregiving, and helped the participants feel noticed, cared for, and happy, which in turn improved their symptoms and their ability to do their day-to-day activities. According to Kleinman, “caregiving is a foundational component of moral experience. It is a practice of acknowledgement, empathic imagination, witnessing, responsibility, solidarity, and the most concrete forms of assistance. It is this moral aspect that makes caregivers, and at times even care-receivers, feel more “present” – and thus more fully human.” (Kleinman, 2009) The findings support the positive role of *accompagnateurs* in caring for people with mental disorders in their own homes and communities; in helping them overcome the barriers and challenges that often condition their illness; and in helping them seek and stay on care.

## **5. Limitations**

Our study has several limitations. First, while our study establishes the reliability and construct validity of the PHQ-9 for diagnosis of depression, the cross-sectional design of the

quantitative phase does not reflect the sensitivity to change of the PHQ-9 over time in this setting, which should be further studied to determine whether it is a valid instrument to monitor clinical outcomes for depression over time. Second, most of the participants in our study were female, which may affect the generalizability of our results. Third, the PHQ-2 score was administered as a part of the PHQ-9 questionnaire, which may have affected the sensitivity and specificity results. A study independently administering the PHQ-2 from the PHQ-9 would be recommended. Despite these limitations, both the PHQ-2 and the PHQ-9 proved to be valid and useful as screening and diagnostic tools for depression in rural primary care settings. Fourth, we used the PHQ-9 as the gold standard to assess the sensitivity and specificity of the PHQ-2 as a screening instrument for depression, which may have affected the results. A study using a different diagnostic tool from the PHQ-9 would be recommended. Fifth, we conducted the study in only one rural community and, therefore, the results may not be generalizable to other primary care settings. Sixth, we only screened participants for major depression and did not consider other mental disorders with similar symptoms to those of depression, which may also have a higher PHQ-9 score. Finally, although the qualitative data showed a positive effect of *accompaniment* on depression, the qualitative sample size of patients with a previous diagnosis of depression receiving accompaniment was small; therefore, further research should be conducted to quantitatively and qualitatively examine its effect on clinical outcomes over time in a larger population.

## **6. Conclusion**

Depression represents a major public health problem in resource-limited settings. An integrated approach including research, policy and evidence-based interventions should be

undertaken in order to effectively deliver mental health care in these settings.

This study allowed us to demonstrate the validity of the PHQ-2 and PHQ-9 for screening and diagnosis of depression and to contextualize these measures with patients' experiences living with depression in rural, resource-limited settings. The PHQ-9 showed good reliability and construct validity for diagnosis of depression among the study population. A PHQ-9 score greater than 9 was associated with statistically significantly lower quality of life scores. Also, when comparing PHQ-9 scores and interview accounts, patterns in the total PHQ-9 score broadly reflected patients' accounts of the severity of their symptoms. However, despite its validity, the PHQ-9 does not assess the presence of physical symptoms, which were largely present among the participants during the qualitative interviews, and were referred to affect the ability of the participants to perform their day-to-day activities and associated with significant disability. Also, participants not always recorded their thoughts of being better off dead than alive accurately on the PHQ-9, and when they did, the PHQ-9 focused on the frequency of symptoms, which may have not reflected patients' own experiences, which may be associated with the intensity of those thoughts. As a purely quantitative assessment scale, the PHQ-9 fails to capture the experience of living with depression, and the role that local culture and beliefs play on how patients conceptualize the disease and, therefore, on their care seeking behavior. Consequently, we would recommend adapting some of the questions of the PHQ-9 to incorporate some of the local idioms and common complaints identified in the interviews, such as "*desesperación*" and "thinking too much"; rephrasing the questions that were more difficult for the participants to understand in a way that they relate to their context and the literacy level of the population; and incorporating some questions about the presence of

physical symptoms, such as headache, stomach pain, muscle and joint pain, diarrhea, vomiting, and lightheadedness when assessing patients for depression.

Given that the PHQ-2 showed good psychometric properties for screening of depression, we recommend for CES to continue to use it, and for primary care practices in rural settings to adopt it as a screening tool in the regular outpatient visits, as the core symptoms that the PHQ-2 assesses would be easy for care providers to remember. For those patients with a PHQ-2 of 3 or greater, we recommend using a contextually adapted version of PHQ-9 for diagnosis of depression.

The findings demonstrated the health and social burden of depression in this setting. The quantitative findings showed that depression was statistically significantly associated with lower quality of life for the physical, psychological and environment domains in this setting. Depression was also associated with perceived social, functional and occupational impairment. The qualitative findings highlighted the negative impact of depression on participants' general sense of wellbeing, affecting their physical and psychological health; their ability to do their day-to-day activities and take care of their loved ones; their personal relationships; and their ability to work.

The qualitative data provided contextual stories to characterize patients' experiences living with depression, which reflected the role of stressful life events as triggers of depression; the presence of feelings of sadness and *desesperación*; the relationship between thinking too much and insomnia, the significant presence of physical symptoms accompanying psychological symptoms; the high frequency and intensity of thoughts of self-harm; the influence of patients' conceptualization and physicians' failure to recognize depressive illness

on care seeking behavior; and the perceived therapeutic effect of *accompaniment* by health providers and community health workers.

Given that depression is multifactorial, any interventions aiming at addressing it should be holistic and take into account not only the causes but also the barriers and challenges for patients to seek care and to remain on treatment. Understanding the influence of society, history and culture on individuals' experience living with and seeking care for depression demands paying attention to the local context in which they live and interact with other individuals, families, communities and institutions. In addition to using quantitative measures to assess individuals for depression, we recommend the adoption of a bio-sociocultural model to develop and implement contextually appropriate strategies to effectively deliver mental health care, and to ultimately improve mental health outcomes in rural, resource-limited settings.

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## 8. Appendices

### Appendix 1. Patient Health Questionnaire-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
	_____	_____	_____	_____
			<b>Total Score:</b>	_____

*“If you have presented any of the symptoms I asked you previously, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?”*

\_\_\_\_\_ **Not difficult at all**    \_\_\_\_\_ **Somewhat difficult**    \_\_\_\_\_ **Very difficult**    \_\_\_\_\_ **Extremely difficult**

From the Primary Care Evaluation of Mental Disorders (PRIME-MD). Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, in collaboration with researchers at the Regenstrief Institute at Indiana University and with the support of an educational grant from Pfizer Inc.



**Appendix 2. WHO Quality of Life BREF Assessment Tool (WHOQOL-BREF)**

		Very poor	Poor	Neither poor nor good	Good	Very Good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied not dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied not dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5

22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, and depression?	5	4	3	2	1

## Appendix 3. Qualitative Interview Guide

### Introductory questions

1. Can you tell me how was your depression diagnosed?
2. What does a diagnosis of depression mean to you?
  - a. How do you feel about it?
3. What do you think caused your depression?
  - a. Can you say a little more about that?
4. What has been your experience of seeking care for your symptoms of depression?
  - a. Could you give me an example of that?
5. Have you faced any barriers or challenges to seek/receive care for your depression?
  - a. If yes, could you describe them to me?
6. How would you describe the process of receiving care for your depression?
  - a. Can you say a little more about that?

### Thinking about the past 2 weeks:

7. How would you describe your health in general?
8. How do you think depression affects your health in general?
  - a. Can you give me an example of that?
9. How have you been feeling recently?
  - a. Can you say a little more about that? Follow up questions related to mood, cognition and function perception
10. How would you describe your sleep patterns?
  - a. What would a typical night look like?
11. How would you describe your appetite and eating habits?
  - a. Could you guide me through what you eat in a typical day?
12. How would you say this episode of depression affect your ability to perform your day-to-day activities, for example, work and caring roles?
  - a. Could you walk me through the different activities that you do in a normal day?
13. To what extent are you enjoying things you would usually enjoy?
  - a. What are the activities that you enjoy most?
14. How do you think depression affects your relationships with your friends and family?
  - a. Could you give me an example of that?
15. Have you had thoughts that you would be better off dead?
  - a. If yes, could you tell me more about those thoughts?
16. Have you thought of hurting yourself in some way?
  - a. If yes, what were those thoughts like?
    - i. Was there any particular situation or circumstance that triggered those thoughts?
17. Have you ever tried to hurt yourself in some way?
  - a. If yes, could you describe the experience for me?
    - i. Was there any particular situation or circumstance that led you to try to hurt yourself?

### Closing question

18. Do you have any other thoughts or questions for me? Is there anything else you would like to add before we end?