Published in final edited form as:

Prog Community Health Partnersh. 2013 ; 7(4): 429–441. doi:10.1353/cpr.2013.0046.

“Tension” in South Asian Women: Developing a Measure of Common Mental Disorder Using Participatory Methods

Alison Karasz, PhD¹, Viraj Patel, MD², Mahbhooba Kabita, MA, and Parvin Shimu

¹Albert Einstein College of Medicine, Department of Family and Social Medicine

²Montefiore Medical Center

Abstract

Background—Though common mental disorder (CMD) is highly prevalent among South Asian immigrant women, they rarely seek mental treatment. This may be due in part to the lack of *conceptual synchrony* between medical models of mental disorder and the social models of distress common in South Asian communities. Furthermore, common mental health screening and diagnostic measures may not adequately capture distress in this group. CBPR is ideally suited to help address measurement issues in CMD as well as develop culturally appropriate treatment models.

Objectives—To use participatory methods to identify an appropriate, culturally specific mental health syndrome and develop an instrument to measure this syndrome.

Methods—We formed a partnership between researchers, clinicians, and community members. The partnership selected a culturally specific model of emotional distress/ illness, “Tension,” as a focus for further study. Partners developed a scale to measure Tension and tested the new scale on 162 Bangladeshi immigrant women living in the Bronx.

Results—The 24-item “Tension Scale” had high internal consistency ($\alpha = 0.83$). In bivariate analysis, the scale significantly correlated in the expected direction with depressed as measured by the PHQ-2, age, education, self-rated health, having seen a physician in the past year, and other variables.

Conclusions—Using participatory techniques, we created a new measure designed to assess common mental disorder in an isolated immigrant group. The new measure shows excellent psychometric properties and will be helpful in the implementation of a community-based, culturally synchronous intervention for depression. We describe a useful strategy for the rapid development and field testing of culturally appropriate measures of mental distress and disorder.

Keywords

Community-based participatory research; community health partnerships; health disparities; process issues; mood disorders; conceptual models of illness; health beliefs; illness representations; mental health

Introduction

South Asian immigrants from India, Pakistan and Bangladesh are the fastest growing immigrant group in the United States¹ (1). Though their population numbers nearly three million, South Asians have received little attention from health researchers. This may be due in part to their reputation as a “model minority” (2), since earlier waves of South Asian immigrants consisted largely of educated professionals who assimilated rapidly and dispersed into suburban communities. However, this pattern has altered sharply in recent years, during which many working class South Asians have made their way to the United States. Newer groups settle in dense, low-income urban neighborhoods that have a high concentration of South Asians. One of newest, fastest growing of these communities is the Bangladeshi community in the Bronx, New York.

In the Bangladeshi immigrant community, as in many of New York City's South Asian groups, emotional distress and common mental disorder are highly prevalent. Women face a special set of economic and social stressors. These include wide spread poverty, discrimination within the host society, and linguistic isolation. Many women also experience stresses related to South Asian gender practices. In many societies across the South Asian subcontinent, women are often marginalized and discounted. Married women are traditionally treated as low status outsiders in their in-laws' households, and after marriage many women are secluded in the home (3, 4). Traditional forms of gender discrimination and abuse, including forced marriages, lack of access to education, and domestic violence (5), (6-8) are not infrequent in some immigrant groups (9-13). Furthermore, immigration itself deprives women of traditional sources of emotional support and protection (14).

This accumulation of social stresses often culminates in emotional distress and symptoms. Studies in South Asia report pronounced gender disparities on most social and health indicators, including mental health (15-19). Early married life, in particular, is associated with high rates of mental and physical illness, suicide and other forms of violent death among South Asian women (20, 21). Though there has been little epidemiological research on South Asian women in the United States, a substantial literature on diasporic communities in Canada and the United Kingdom documents the high prevalence of common mental disorder (CMD) among immigrant women, particularly in Muslim communities (22-24). Furthermore, very high rates of self harm, suicide attempts, and completed suicides among South Asian women immigrants suggest that true prevalence rates of CMD may be underestimated (25-29). Young married South Asian women in the UK are three times more likely to attempt suicide than their white counterparts, and seven times more likely to complete a suicide attempt than South Asian men.

Despite high levels of common mental disorder, South Asian immigrant women seek traditional mental health treatments in low numbers. Like persons from other ethnic minority communities, as well as the elderly (30) and low income groups (31), Asian Americans are less likely to initiate treatment or to be prescribed optimum levels of treatment than middle class European Americans. When experiencing emotional distress, South Asians frequently consult their primary care physicians, to whom they are more likely to present medically unexplained somatic symptoms than emotional distress (32-34).

It has been argued that contrast between high rates of mental distress and CMD and low rates of mental health treatment among South Asian immigrants—as among other low income and ethnic minority communities—arises from a *conceptual gap* between the psychiatric models of mental disorder and conceptual models of distress among community members (35-37). Standard treatment models for mental disorders in western societies are premised on a biopsychiatric framework of illness and care in which mental distress and disorder are conceptualized as pathology of the individual most effectively addressed with pharmacological and other technical treatments. Yet outside of mental health treatment settings and randomized controlled trials, many individuals, especially those from low income and ethnic minority groups, conceptualize their symptoms in social terms as a relatively normal response to life problems and situations. Individuals reporting social models are wary of technical treatments and less likely to seek them out than those reporting psychiatric models (38).

Public health campaigns such as the “Beyond Blue” campaign in Australia and the “Defeat Depression” campaign in the UK conceptualize these cultural and social class differences as “low mental health literacy” and have worked to “educate” the public regarding the biomedical causes and treatments of common mental disorder. Considerable public funds have been expended in public campaigns designed to alter popular conceptions of depression and related illness to bring them into line with current biomedical concepts (39-41). These campaigns have met with limited success, however, and in most countries the rates of treatment utilization for persons experiencing depression and related problems remain low (42, 43).

A number of studies have examined conceptual models of depression and related disorders in South Asian women (44,45). These studies show that South Asian women conceptualize depression symptoms as a *relatively normal response* to social problems. They are less likely to attribute symptoms of distress such as sadness, exhaustion, or anxiety to psychological or neurological abnormalities, compared with European Americans or to view professional treatment as necessary. Studies in South Asia and in immigrant communities have found that “depression” or its equivalents are rarely used as a label for these symptoms; in fact, the term “depression” is often understood to represent a severe mental disorder, accompanied by psychotic symptoms, that is conceptually distinct from the everyday, socially based symptoms associated with CMD. In place of depression or other psychiatric terms, participants propose labels emphasizing worry and anxiety related to life situations. Terms such as “thinking too much” “Chinta” (worry) or “chinta rog” (worry sickness) are common terms. “Tension” or “tension rog” (tension sickness) are also common illness terms across South Asian societies and generally refer to a constellation of emotional and physical symptoms including sadness, worry, fatigue, weakness and pain (46-48).

Among South Asians, depressive and anxiety symptoms are generally viewed a predictable—and natural—response to real life problems—family conflict, marital problems, loneliness, the loss of close family ties, and financial problems. Because South Asian participants conceptualize such problems in social terms, they are far less likely than European Americans to seek professional treatments focusing on individual pathology. Distraction, placating powerful others such as the husband or in-laws, seeking advice from family

members, and talking with close friends to get relief are commonly mentioned help seeking strategies (35, 46,49).

The Bondhu Project

Studies of psychological treatment and healing in cross-cultural settings indicate the importance of a conceptual synchrony between the patient and the healer or treatment system (50). When synchrony is absent—when the “meaning” of treatment fails to match with the patient's explanatory models of illness and care—the healing process can falter (51-53). Thus, developing treatment models that incorporate patients' conceptual models of illness and care is an important key to addressing the current efficacy-effectiveness gap in mental health treatment.

Community-based participatory research (CBPR), which emphasizes the values, beliefs and knowledge of the community, would seem ideally suited to the development of culturally sensitive treatment models of mental disorder. Surprisingly, there have been relatively few CBPR projects focusing on mental health (54)(54)(55) A recent review (54) notes that despite evidence that community members in immigrant and minority populations seek innovative mental health approaches that incorporate culturally shaped concepts of mental health and illness, most CBPR projects utilize conventional methods, models and assessment tools derived from a health services perspective. Common approaches include developing community education strategies designed to reduce the conceptual gap (56); or working collaboratively with stakeholders improve detection and access to traditional mental health treatments (55).

An alternative approach is to partner with the community in developing interventions that incorporate cultural models or idioms of distress and are in synchrony with community perceptions of the nature, cause, and treatment of CMD. Surprisingly, there have been very few studies documented in the CBPR literature that use such an approach (54)1. The Bondhu (“friend” in Bengali) Project was a community based participatory research project on common mental disorder conducted in a Bangladeshi immigrant community in 2007-2008. The project was designed to generate preliminary data in preparation for the implementation of a culturally synchronous mental health intervention for south Asian women immigrants. In Phase 1 of the project, we used participatory, dialogic methods to explore cultural models of distress and illness through a partnership between researchers, clinicians, and community members. In this report, we describe the identification of a cultural syndrome, ‘tension,’ as a focus for the project, and the development and testing of a scale to assess this syndrome.

The project was approved by the Albert Einstein College of Medicine IRB.

Methods

Forming a partnership

Our goal was to design an intervention that would be appropriate for women least likely to utilize conventional mental health treatments: i.e., less acculturated, more recent immigrants

from low income inner city communities. We therefore located our project in a public health clinic in the heart of a dense, urban Bangladeshi neighborhood in the Bronx, New York. The Bangladeshi community is the newest South Asian immigrant community in New York. Though there has been little research in this group, a few studies have found group higher rates of unmet health and social services needs, higher rates of health problems, and lower levels of English skills than in other groups (57) (65).

The initial project planning team included a physician, a health advocate, and several researchers. The physician was the medical director of the clinic and was well known and highly regarded in the local community. She and her staff spread the word among clinic patients and through word of mouth that we would be recruiting community partners for a research project.

The planning team anticipated that recruitment would be a difficult and lengthy process. We therefore planned to engage participants through a series of outreach meetings that would take place over several months. We planned to distribute fliers throughout the neighborhood and identify other recruitment strategies. We hoped to recruit twelve partners, on a first come first serve basis, over a period of three months. Although we recognized that this strategy would result in a less representative sample than a more complex sampling plan, we felt this to be the most practical, as well as the fairest option.

On the day of our first outreach meeting in the clinic, sixteen women attended. We introduced ourselves, described the project, and answered questions. The following week a second meeting was held in the clinic. We expected that only a few members from the first week would attend. However, all sixteen were present. Furthermore, *nearly forty additional women* also attended the meeting.

After some discussion, we decided that the fairest option was to offer the sixteen original members participation on the project and add the remaining women to a waiting list.ⁱ

We worked with our sixteen community partners to develop a cohesive, functioning, partnership. Early phases of Bondhu formation involved strengthening bonds between members and developing healthy group processes. Efforts were made to develop procedures that support and reinforce key principles of CBPR such as building equity, sharing control over decision making, and respect for cultural differences and perspectives (58).

Confidentiality was addressed at length in the group. Developing group cohesiveness was another important task of the early phase of a partnership. A variety of techniques, such as the use of games and icebreakers, were used for this purpose (59).

Conceptualizing the problem

Once the group had been formed, we moved on to the second step: conceptualizing the problem. In its purest form, CBPR projects involve the identification of a research problem

ⁱWhen we announced this decision at the third meeting, women on the waiting list were very disappointed. Several of them asked the planning team to create a program for them. After some discussion, we invited them back to meet with us again. We suggested that they start meeting on their own, and offered to provide support on group facilitation and planning skills. This group, which chose the name the "Mothers' Club," began meeting in 2007 and has been meeting continuously for five years.

though dialogue with community members. However, most research grants are provided by funders with specific funding interests, often disease-specific. The grant received for this project was from the National Institute of Mental Health and required us to focus on mental disorders. Based on the literature identifying common mental disorder (CMD) as a major health issue among South Asian women, we decided to focus on CMD in our partnership and intervention development project. We found that women readily recognized, and acknowledged, the symptoms of CMD—sadness, anxiety, and related physical distress-- as a key health issue in their lives.

Although we focused the project originally on a broad category—"Common mental disorder"—we planned to work with our partners to identify a more specific, cultural specific, mental health syndrome that would be the focus of the project. As we saw it, the identification of a shared illness category was a key step in the development of a culturally synchronous mental health treatment. It was assumed ahead of time that conventional psychiatric categories such as 'depression' or 'anxiety' would not translate well into the Bangladeshi cultural context. Mental health workers in cross cultural settings note that the use of western diagnostic terms may be off-putting to patients from non-western cultures (60) and that new treatment models for psychological distress are more likely to succeed if they are based on an understanding of local ways of articulating distress. A common, shared term for the illness problem lessens the possibility that the treatment itself will be seen as 'alienating or imposed' (60). Without a common language to describe the illness problem, we believed it would be difficult to communicate with the larger community about our program, to publicize it and ultimately to recruit patients into our intervention. Furthermore, we expected that though many of the symptoms defining the western syndrome of "Major Depression" might be familiar to women, as symptoms of common mental disorder experienced in many cultural settings, the syndrome itself might have limited relevance as an expression of distress in the Bangladeshi context. Instead, we expected that Bangladeshi women would identify an overlapping, but distinct syndrome with its own cultural meanings.

To identify an appropriate local illness category, we used participatory methods to identify a culturally meaningful syndrome to serve as the focus of our work. The group spent many meetings discussing women's emotional distress, its social context, and its antecedents in family and social life. In discussions of family and social problems such as isolation in the home, financial problems, issues with immigration status, domestic conflict and abuse, participants emphasized the disempowerment, lack of status, and humiliation that are common features of women's lives.

The partners discussed a variety of potential syndromes or problems. The term 'depression' was discussed in turn, and dismissed as a rare, severe disorder in which people acted 'pagal' (crazy). The syndrome that was chosen to work on was 'tension,' a common illness category in South Asia that is frequently reported in the literature, including the previous work of the first author ((49)).

As this preliminary research indicated, and as confirmed through conversations with our community partners, "tension" is a syndrome that varies in severity and chronicity. At its

most severe, it is considered a highly dangerous illness that can lead to health problems including hypertension, cardiovascular disease, and madness, while milder forms are equivalent to the English equivalent of 'stress.' Importantly, 'tension' is considered a condition of social origin. Women described tension as a response to the stresses of life in the United States: the loss of social status, poverty, poor housing conditions, and a general sense of disappointed hopes. The other major cause of tension was loneliness, following the separation from family and friends. Gender related issues, including psychological and physical abuse, low status within the family (46), conflict with the husband or in-laws, and a humiliating lack financial independence, were another important antecedent of 'tension.'

We also spent a great deal of time talking about the 'treatment' or 'solutions' to the problem of tension. Many participants expressed the view that tension was an unavoidable part of life and especially common in women's lives. Common ways of addressing and alleviating tension were discussed. Advice and support from close family, especially mothers and sisters, was the most common source of strength and comfort, in some cases women sought help from husbands and older children. Having a close confidant was seen as the most important asset in coping with tension. Prayer and reading the Quran were also frequently mentioned. Other self help strategies included distraction--getting out of the house, watching TV or listening to music, or 'resting.'

Conversations with participants suggested themes reflected in other research on non-western cultural models of depression and its treatment. As expected (35, 46) women almost never mentioned formal, medical or psychological treatment as appropriate for 'tension.' When the research and clinical partners raised this possibility, women responded without enthusiasm. Several mentioned that they had seen advertisements for depression treatment on television, but that they did not believe these treatments would be effective for a condition that was of social origin. However, in a few cases women noted that tension could cause physical health problems such as fatigue, weakness, heart disease or hypertension. In such cases, they believed that medical treatment was necessary.

Importantly, "tension" is manifest through both physical as well as emotional distress. Though Western diagnostic categories of mental disorder emphasize psychological symptoms, in keeping with a tendency to 'psychologize' distress that is widespread in advanced western societies, individuals from non-western societies often communicate distress through somatic symptoms. In 'tension,' emotional symptoms such as anxiety, worry, anger, and sadness, are similar to those associated with common mental disorder in the west; while physical symptoms include a wide variety of somatic expressions and manifestations of distress such as pain, gastrointestinal symptoms, and fatigue, as well as culture-specific symptoms such as leucorrhea, a white vaginal discharge associated with marital distress and conflict in South Asia (61).

Developing an instrument

Once the construct of 'tension' was selected, the team decided to operationalize this construct through the systematic development of an instrument that could be used in the needs assessment and the intervention. Although this suggestion came from the researchers in the partnership, it was proposed to the group and discussed in detail; ultimately the group

made the decision to move ahead with instrument development. We had two goals for developing the instrument. The first goal was to establish a common meaning for ‘tension’ as a syndrome that could facilitate communication with the community about the focus of our project. In discussing the purpose of the intervention with community members, the scale itself could be used to clarify a shared meaning for the term. In addition to this programmatic goal, we also speculated that the new scale might be helpful as a research tool. Ultimately, it might help to refine diagnostic criteria for recruitment into the group and could function as a potential measure of the effects of the treatment.

Once the partnership had decided to develop a measure of ‘tension,’ the first author (AK) recruited several Bondhu members and developed a working group for the project. These group members volunteered for the working group because they were interested in acquiring research skills and experiences and in learning more about women's tension within the community. The group met about 8 times over several months.

A variety of techniques have been used in cross-cultural settings to develop new measures of mental disorder. One typical method is to conduct qualitative interviews with community members and extract symptoms from the qualitative data (62). Other researchers have used key informants, such as clinicians or local healers, to develop instruments. Another method that is occasionally used is free listing, in which stakeholders generate lists of symptoms associated with an illness category (63). We used a modified free listing technique to develop our Tension Scale.

In the first phase of instrument development, members of the “Tension Group” received training from the first author in interviewing techniques, data recording, and ethical issues. Next, they recruited and conducted three interviews each with women from the community. This number was chosen as a preliminary step; group members felt that three interviews would be easy to accomplish. We spent considerable time discussing the process of interviewing. Group members raised concerns about what it would be like to discuss very personal and upsetting issues with their fellow community members. We provided advice on how to approach participants, how to ‘manage’ emotion that might emerge, and what to do if any interviewee seemed to desire or need further help.

Since the goal of the overall project was to identify a syndrome and design an intervention for unacculturated women least likely to seek out conventional mental treatments, we asked our Tension Group members to identify friends and neighbors likely to fit into this category. We described the ideal participant as ‘similar’ to our Tension Group members—recent immigrants, primarily Bengali-speaking. Interviews focused on participants' understanding of the meaning and experience of ‘tension.’ Participants were asked to list at least six feelings or symptoms of tension including both emotional and physical symptoms

At the conclusion of the interviewing process, group members met to discuss their findings. A list of nearly forty symptoms emerged from the interviews. During the review discussions, the group added several symptoms that were missing. For example, ‘vaginal discharge,’ a common cultural symptom commonly associated with distress and tension, had not been included in the original list – perhaps because participants hesitated to bring up this

symptom spontaneously. The tension research group, however, agreed that vaginal discharge was a common symptom of tension. Similar terms were merged together following group discussion. A few listed symptoms were dropped from the list when group members did not feel they were relevant to the syndrome 'tension.' In a second step, women took the symptom checklist into the field and tested it on a new set of 12 participants. Participants were asked to check off the symptoms they experienced during periods of 'tension.' In discussions that followed, symptoms checked less than twice were dropped from the list. We fitted the remaining 24 symptoms to a 4 point Likert scale preceded by the question: "Over the past 2 weeks, how often have you been bothered by any of these problems." Responses were scored 1 through 4 with the following categories: 'not at all,' 'several days,' 'more than half the days,' and 'almost every day' respectively, with options for 'don't know' and 'refused'. The only exception to this scoring was one item: 'hair becoming white,' which was scored 1 through 3: 'not at all,' 'some,' or 'a lot' (Table 1).

Preliminary Test of the Tension Scale—The resulting instrument was then inserted into a larger community based health needs assessment survey of Bangladeshi women in the Bronx. The survey, which is described in detail elsewhere (64) was conducted by the Westchester Square Partnership (WSP), a non-profit community based organization that was founded by the original partners in the Bondhu project and currently serves the New York City South Asian community. WSP administered the survey with the goal of assessing health needs of women in its target community. The survey included questions from the 2008 and 2009 New York City Community Health Survey (65) on health history, health behaviors, health care access, and sociodemographics. Additionally, we included the two-item Patient Health Questionnaire (PHQ-2), a depression screening tool commonly used in clinical practice. A positive score on the PHQ-2 indicates risk of depressive disorder (66). We chose the PHQ-2 because of its brevity, its comparable predictive utility as compared with the PHQ-9, and its wide use in international settings (67-70) Community Health Workers translated and back-translated the overall survey from Bengali and pre-tested the Bengali version with the Bondhu members, incorporating changes as necessary prior to administration in the community.

Recruitment: The Westchester and Parkchester neighborhoods of the Bronx, with their heavy concentration of Bangladeshi immigrants, were selected for the survey. Bangladeshi community health workers (CHWs) used a community mapping approach in order to identify Bangladeshi households. Based on the knowledge of Bondhu group members and the community health workers, buildings known to have high concentrations of Bangladeshi residents were selected for visits by the data collection team. CHWs visited the selected buildings between September and November 2009. Inclusion criteria for participation in the study included age 18 or above, female sex, Bangladeshi country of origin, and ability to speak Bengali or English. Response rates were high, with 97% of respondents completing the Tension Scale.

Data Collection: CHWs obtained informed consent and administered the questionnaire orally in Bengali to survey participants in the respondents' home. In situations where more

than one Bangladeshi woman 18 years old or over lived in the home, the woman answering the door was asked to participate.

Analysis: Analyses for testing the validity of the Tension Scale were carried out by the first and second authors. Data was compiled and entered directly into a Microsoft Access database. Survey data was cleaned and analyzed using STATA Intercooled version 11 (StataCorp, College Station, Texas). Descriptive statistics were examined for outliers. Income to federal poverty level (FPL) ratios were calculated using family size and reported income, and participants were classified dichotomously as above or below the FPL.

Missing data was minimal for the tension scale items (only six observations for 24 items among the 162 respondents were missing) and multiple imputation was used to generate estimated values for analysis. Exploratory factor analysis was used to evaluate variance in the developed scale. A “tension score” was generated by summing the 24 items on the scale and this score was then used for all further analysis. Internal consistency was assessed using Cronbach's Alpha test. To assess concurrent validity, we conducted a bivariate analysis using Pearson's *r* to correlate the relationship between the Tension Scale and sociodemographic and health indicators (e.g. poverty, education, diagnosis of diabetes, hypertension, hyperlipidemia, engagement in physical activity, and breast and cervical cancer screening activities) known to relate to depression. We also examined the relationship between PHQ-2 scores and the Tension Scale.

Results

Sample—Of the 769 homes approached by the CHWs, 184 were Bangladeshi households, 585 other, and 14 households could not be reached. Of the 184 Bangladeshi women reached, 91% (n=167) consented and participated in the 1st wave of the survey, with 17 refusing. 97% of the respondents (n=162) completed the second wave of data collection including the tension scale (Figure 1).

Table 2 shows demographic and health characteristics of the tension scale respondents in the sample. Participants were relatively young. They reported low levels of formal education and poor English language skills. Questions about income yielded the lowest response rate with 46.9% reporting “don't know” or refusing to answer the question. But of the women who did provide household incomes, majority reported incomes below poverty level (54.6%) while another third reported incomes between 100-200% of the federal poverty level. The women in the sample were relatively new immigrants, with the median of four years in the United States and a mean 5.5 years (SD±4.7). Given the overall youth of the sample, participants had surprisingly high rates of known diabetes (10.5%), hypertension (19.1%), and hyperlipidemia (25.3%) and very low levels of engagement in physical activity. These results have been discussed in detail elsewhere (64). Based on the PHQ-2, 37.7% (n=61) screened positive for risk of depression.

Analysis of the Tension Scale

Of a total score of 95, the mean score ± SD was 38.6 ± 9.3.

Reliability—Internal consistency, indicated by Cronbach's alpha, was 0.83 for the entire scale with all items having an individual item-scale correlation of 0.81 or greater.

Validity—A factor analysis was performed as an initial test of the validity of the scale. Results of the factor analysis were ambiguous. One factor, consisting of psychological and somatic symptoms, accounted for over 54% of the variance; while a second factor, consisting of somatic symptoms, accounted for about 14%.

In a preliminary test of the external validity of the scale, we assessed correlations between the Tension Scale and demographic and health factors known to be correlated with depression or mental distress (Table 3). As expected, the Tension Scale strongly correlated with the PhQ-2 ($r = .483$, $p < .0001$). Since the scale includes one symptom (sadness) similar to that on the PHQ-2, we conducted an analysis of the correlation between the two measures without the including this common symptom. The result was largely similar with only a slight decrease in the correlation coefficient ($r = 0.442$, $p < 0.0001$). In bivariate analysis, the scale also correlated ($p < .05$) with health indicators in the expected direction, including age, body-mass index, waist circumference, hypertension, hyperlipidemia, and emergency room use. As we expected, the scale was inversely correlated at a significant level ($p < .05$) with education, income to Federal-Poverty-Level ratios, seeing a physician in the past 12 months, self-rated general health (higher number indicating better health), and self-rated diet.

Discussion

This project used a participatory process to develop an instrument for measuring a locally defined category of common mental disorder. A team of researchers and clinicians worked with community members to identify a cultural syndrome. In a second step, we developed an instrument for assessing tension-related distress, and tested the instrument on a sample of 154 community members. Community members were engaged at each step of the process, including choice of the syndrome, initial conceptualization, and instrument testing. Community members also reviewed the results of this paper.

Although community based participatory research projects on mental health have been reported in the literature, these projects often focus on psychiatric diagnoses such as depression and anxiety. A recent review of mental health research projects using a CBPR was critical of the somewhat conventional models and methods used in many of these projects. Our approach was more radical and more participatory. We based our work on the assumption that mental illness categories, including those that constitute the DSM and related psychiatric classification systems, reflect *cultural concepts* of illness, suffering, and the relationship between self and society. As a result, we worked with our community partners to identify a local cultural syndrome as a focus of the project. “Tension,” a widely reported distress/illness category in the South Asian context, includes both physical and emotional manifestations of distress.

The Tension Scale remains to be tested further. A Factor Analysis did not completely support a one-factor solution, and further studies using larger samples will examine whether the scale may be broken down into subscales. However, in other respects the showed good

psychometric properties, including a high inter-item reliability and correlations in the expected direction with socio-demographic and health variables. Furthermore, our tension project illustrates a practical and novel strategy for conducting participatory research on mental health issues in cross-cultural settings.

The Tension Scale that was developed in this study was also an important element in the planning and development of a culturally synchronous mental health treatment, to be described in a later paper. The illness category “Tension” has the advantage of being quickly recognizable to community members. When we talk with community members about their tension, we do not need to convince them that they suffer from a potentially stigmatizing ‘mental disorder’ such as depression. *“Tension” is a widely recognized, relatively unstigmatizing distress syndrome of social origin.*

The study has several important limitations. First, the sample was limited to a particular South Asian group—new women immigrants from the Bangladesh. Our project targeted recent, relatively unacculturated immigrants since these are the most likely to suffer from CMD and are also least likely to seek out conventional western mental health treatment. However, though we worked only with Bangladeshi immigrants in this project, we believe that our method and our findings may be relevant to other immigrant communities from the South Asian subcontinent. Despite broad variations in language, religion, diet, etc., most scholars agree that societies of South Asia, particularly those of the ‘purdah belt,’ a broad region stretching across the northern part of India that includes Pakistan and Bangladesh, broadly constitute a culture area that shares many social, structural and cultural characteristics. The Tension Scale we developed for the study includes symptoms that have been reported in studies of other South Asian groups (24, 49, 71-73). However, the degree to which the scale is appropriate for use with other groups is an empirical question that will be answered in future research.

Future research

As a *research instrument*, the scale needs to be further tested and its relationship to important psychological and social variables, such as poverty, life stress, and illness, elucidated. Our preliminary evidence suggests that the tension scale, as a locally developed measure of distress and CMD, may be more sensitive to such variables than western-developed measures of depression such as the PHQ. If validated in further studies, the Tension Scale has potential as a tool in epidemiological studies of South Asian immigrant communities, helping to elucidate relationships between social context and emotional symptoms. As a *clinical instrument*, the Tension scale has several potential uses. First, as we discuss above, the scale provides a shared definition for common mental disorder that may help patients assess their own distress, as well as facilitate a shared understanding between clinicians and patients. The common term, ‘tension,’ is imprecise—its meanings vary considerably among speakers and across situations. By operationalizing ‘tension’ as a scale, we established a common vocabulary that can be readily understood by all participants in the treatment setting.

Second, the scale may have value as a clinical tool for identifying individuals in distress or in need of help, or as a measure of response to treatment. Further, larger scale studies are

needed to establish the scale's usefulness for identifying distress in at-risk populations, such as primary care patients. Our team has used the Tension Scale to assess response to treatment in a depression treatment program for Bangladeshi women. We will report results in a future paper.

Acknowledgments

We would like to acknowledge the invaluable help and support of Shibani Roy, Mursheda Begum, Sukriya Begum, and Nazneen Akhter, all of whom participated in the development of the Tension Scale, and all of whom helped to collect the survey data. We would also like to acknowledge Drs. Jean Burg and Runi Mukherji, members of the Bondhu partnership group, and Dr. Rosy Chhabra, who facilitated the group meetings. All three provided valuable conceptual input into the project.

References

1. Islam NS, Khan S, Kwon S, Jang D, Ro M, Trinh-Shevrin C. Methodological issues in the collection, analysis, and reporting of granular data in asian american populations: historical challenges and potential solutions. *J Health Care Poor Underserved*. 2010; 21(4):1354–1381. [PubMed: 21099084]
2. Mahmud T. Genealogy of a state-engineered 'Model Minority' 'Not quite/not white' South Asian Americans. *Denver Univ Law Rev*. 2001; 78(4)
3. Mandelbaum, D. Women's seclusion and men's honor: Sex roles in North India, Bangladesh, and Pakistan. Tucson: University of Arizona Press; 1988.
4. Rauf A. Rural women and the family: A study of a Punjabi village in Pakistan. 1987; 18(3):403–415.
5. Raj A, Silverman JG. Immigrant South Asian women at greater risk for injury from intimate partner violence. *Am J Public Health*. 2003 Mar; 93(0090-0036; 3):435–437. [PubMed: 12604489]
6. Preisser AB. Domestic violence in south Asian communities in America: Advocacy and intervention. *Violence Against Women*. 1999; 5(6):684–699.
7. George MS, Rahangdale L. Domestic violence and South Asian women. *N C Med J*. 1999 May; 60(0029-2559; 3):157–159. [PubMed: 10355280]
8. Raj A, Silverman JG. Intimate partner violence against South Asian women in greater Boston. *J Am Med Womens Assoc*. 2002; 57(0098-8421; 2):111–114. [PubMed: 11991419]
9. Raj A, Silverman JG, McCleary-Sills J, Liu R. Immigration policies increase south Asian immigrant women's vulnerability to intimate partner violence. *J Am Med Womens Assoc*. 2005; 60(1551-8221; 1):26–32. [PubMed: 16845767]
10. Raj A, Liu R, McCleary-Sills J, Silverman JG. South Asian victims of intimate partner violence more likely than non-victims to report sexual health concerns. *J Immigr Health*. 2005 Apr; 7(1096-4045; 2):85–91. [PubMed: 15789160]
11. Abraham M. Isolation as a form of marital violence: The South Asian immigrant experience. *Year of Publication. Journal of Social Distress & the Homeless*. 2000; 9(3):221–236.
12. Abraham, M. Fighting Back: Abused South Asian Women's Strategies of Resistance. In: Sokoloff, NJ.; Pratt, C., editors. *Domestic violence at the margins: Readings on race, class, gender, and culture*. New Brunswick, NJ, US: Rutgers University Press; 2005. p. 253-271. References
13. Ahmad F, Riaz S, Barata P, Stewart DE. Patriarchal Beliefs and Perceptions of Abuse Among South Asian Immigrant. *Violence Against Women*. 2004; 10(3):262–282.
14. Purkayastha B. Liminal lives: South Asian youth and domestic violence. *Journal of Social Distress & the Homeless*. 2000; 9(3):201–219.
15. Jambunathan J. Sociocultural factors in depression in Asian Indian women. *Health Care Women Int*. 1992 Jul; 13(3):261–270. [PubMed: 1399866]
16. Ulrich H. A study of change and depression among Hanik Brahmin women in a South Indian village. *Cult Med Psychiatry*. 1987; 11:261–287. [PubMed: 3677776]

17. Patel V, Weiss HA, Kirkwood BR, Pednekar S, Nevrekar P, Gupte S, et al. Common genital complaints in women: the contribution of psychosocial and infectious factors in a population-based cohort study in Goa, India. *Int J Epidemiol.* 2006 Dec; 35(0300-5771; 6):1478–1485. [PubMed: 16997847]
18. Mumford DB, Saeed K, Ahmad I, Latif S, Mubbashar MH. Stress and psychiatric disorder in rural Punjab. A community survey. *Br J Psychiatry.* 1997 May; 170:473–478. [PubMed: 9307700]
19. Mahbub ul Haq Human Development Center. Human development in south Asia 2005: Human security in South Asia. 2005
20. Kumar V. Poisoning deaths in married women. *J Clin Forensic Med.* 2004 Feb; 11(1353-1131; 1): 2–5. [PubMed: 15261005]
21. Coomaraswami R. The varied contours of violence against women in South Asia. 2005
22. Weich S, Araya R. International and regional variation in the prevalence of common mental disorders: do we need more surveys? *Br J Psychiatry.* 2004 Apr; 184(0007-1250):289–290. [PubMed: 15056570]
23. Weich S, Nazroo J, Sproston K, McManus S, Blanchard M, Erens B, Karlsen S, King M, Lloyd K, Stansfeld S, Tyrer P. Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med.* 2004; 34(8):1543–1551. [PubMed: 15724884]
24. Bhui K, Bhugra D, Goldberg D, Sauer J, Tylee A. Assessing the prevalence of depression in Punjabi and English primary care attenders: the role of culture, physical illness and somatic symptoms. *Transcult Psychiatry.* 2004 Sep; 41(1363-4615; 3):307–322. [PubMed: 15551723]
25. Cooper J, Husain N, Webb R, Waheed W, Kapur N, Guthrie E, et al. Self-harm in the UK : Differences between South Asians and Whites in rates, characteristics, provision of service and repetition. *Soc Psychiatry Psychiatr Epidemiol.* 2006; (0933-7954) 07/12.
26. Husain MI, Waheed W, Nusrat H. Self-harm in British South Asian Women: Psychosocial Correlates and Strategies for Prevention. *Ann Gen Psychiatry.* 2006; 5(1744-859; 1):7. 05/22. [PubMed: 16716216]
27. Bhugra D. Suicidal behavior in South Asians in the UK. *Crisis.* 2002; 23(0227-5910; 3):108–113. [PubMed: 12542108]
28. Bhugra D, Baldwin DS, Desai M, Jacob KS. Attempted suicide in west London, II. Inter-group comparisons. *Psychol Med.* 1999 Sep; 29(0033-2917; 5):1131–1139. [PubMed: 10576305]
29. Patel SP, Gaw AC. Suicide among immigrants from the Indian subcontinent: a review. *Psychiatr Serv.* 1996 May; 47(1075-2730; 5):517–521. [PubMed: 8740494]
30. Callahan CM, Dittus RS, Tierney WM. Primary care physicians' medical decision making for late-life depression. *J Gen Intern Med.* 1996 Apr; 11(4):218–225. [PubMed: 8744879]
31. Williams D, Teljeur C, Bennett K, Kelly A, Feely J. Influence of material deprivation on prescribing patterns within a deprived population. *Eur J Clin Pharmacol.* 2003 Oct; 59(0031-6970; 7):559–563. [PubMed: 12942224]
32. Jacob KS, Bhugra D, Lloyd KR, Mann AH. Common mental disorders, explanatory models and consultation behaviour among Indian women living in the UK. *J R Soc Med.* 1998 Feb; 91(0141-0768; 2):66–71. [PubMed: 9602740]
33. Bhatt A, Tomenson B, Benjamin S. Transcultural patterns of somatization in primary care: a preliminary report. *J Psychosom Res.* 1989; 33(0022-3999; 6):671–680. [PubMed: 2621670]
34. Commander MJ, Odell SM, Surtees PG, Sashidharan SP. Care pathways for south Asian and white people with depressive and anxiety disorders in the community. *Soc Psychiatry Psychiatr Epidemiol.* 2004 May; 39(0933-7954; 4):259–264. [PubMed: 15085326]
35. Karasz A, Dempsey K. Health seeking for ambiguous symptoms in two cultural groups: a comparative study. *Transcult Psychiatry.* 2008 Sep; 45(1363-4615; 3):415–438. [PubMed: 18799641]
36. Karasz A, Garcia N, Ferri L. Conceptual Models of Depression in Primary Care Patients: A Comparative Study. *J Cross Cult Psychol.* 2009 Nov 1; 40(6):1041–1059. [PubMed: 20182550]
37. Pill R, Prior L, Wood F. Lay attitudes to professional consultations for common mental disorder: a sociological perspective. *Br Med Bull.* 2001; 57(0007-1420):207–219. [PubMed: 11719919]

38. Brown C, Dunbar-Jacob J, Palenchar DR, Kelleher KJ, Bruehlman RD, Sereika S, et al. Primary care patients' personal illness models for depression: a preliminary investigation. *Fam Pract.* 2001 Jun; 18(3):314–320. [PubMed: 11356741]
39. Jorm AF, Christensen H, Medway J, Korten AE, Jacomb PA, Rodgers B. Public belief systems about the helpfulness of interventions for depression: associations with history of depression and professional help-seeking. *Soc Psychiatry Psychiatr Epidemiol.* 2000 May; 35(5):211–219. [PubMed: 10941996]
40. Lauber C, Nordt C, Falcato L, Rossler W. Do people recognize mental illness? Factors influencing mental health literacy. *Eur Arch Psychiatry Clin Neurosci.* 2003 Oct; 253(0940-1334; 5):248–251. [PubMed: 14504994]
41. Goldney RD, Fisher LJ, Wilson DH. Mental health literacy: an impediment to the optimum treatment of major depression in the community. *J Affect Disord.* 2001 May; 64(0165-0327; 2-3): 277–284. [PubMed: 11313096]
42. Nemec K. Public health depression initiative: A review of depression campaigns--lessons for New Zealand. 2005
43. Paykel ES, Hart D, Priest RG. Changes in public attitudes to depression during the Defeat Depression Campaign. *Br J Psychiatry.* 1998 Dec; 173:519–522. [PubMed: 9926082]
44. Karasz, AK. Role strain and symptoms in a group of Pakistani immigrant women. City University of New York: 1998.
45. Lawrence V, Murray J, Banerjee S, Turner S, Sangha K, Byng R, et al. Concepts and causation of depression: a cross-cultural study of the beliefs of older adults. *Gerontologist.* 2006 Feb; 46(0016-9013; 1):23–32. [PubMed: 16452281]
46. Karasz A. Cultural differences in conceptual models of depression. *Soc Sci Med.* 2005 Apr; 60(0277-9536; 7):1625–1635. [PubMed: 15652693]
47. Selim N. Cultural dimensions of depression in Bangladesh: A qualitative study in two villages of Matlab. *Journal of Health, Population and Nutrition.* 2010; 1:95–106.
48. Ahmed SM, Chowdhury M. Micro-credit and emotional well-being: Experience of poor rural women from Matlab, Bangladesh. *World Development.* 2001; 29(11):1957–1966.
49. Karasz A, Dempsey K, Fallek R. Cultural differences in the experience of everyday symptoms: a comparative study of South Asian and European American women. *Cult Med Psychiatry.* 2007 Dec; 31(0165-005; 4):473–497. [PubMed: 17985219]
50. Kleinman, A. Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry. Berkeley: University of California; 1980.
51. Kleinman A. Anthropology and psychiatry. The role of culture in cross-cultural research on illness. *Br J Psychiatry.* 1987 Oct; 151(0007-1250):447–454. [PubMed: 3447661]
52. Kleinman, A. Social origins of distress and disease : depression, neurasthenia, and pain in modern China. New Haven: Yale University Press; 1986.
53. Kleinman A. The cultural meanings and social uses of illness. A role for medical anthropology and clinically oriented social science in the development of primary care theory and research. *J Fam Pract.* 1983 Mar; 16(3):539–545. [PubMed: 6827232]
54. Stacciarini JM, Shattell MM, Coady M, Wiens B. Review: Community-based participatory research approach to address mental health in minority populations. *Community Ment Health J.* 2011 Oct; 47(5):489–497. [PubMed: 20464489]
55. Wells K, Miranda J, Bruce ML, Alegria M, Wallerstein N. Bridging community intervention and mental health services research. *American Journal of Psychiatry.* 2004 Jun; 161(6):955–63. [Review] [97 refs]. [PubMed: 15169681]
56. Chung B, Corbett CE, Boulet B, Cummings JR, Paxton K, McDaniel S, et al. Talking Wellness: a description of a community-academic partnered project to engage an African-American community around depression through the use of poetry, film, and photography. *Ethn Dis.* 2006 Winter; 16(1 Suppl 1):S67–78. [PubMed: 16681130]
57. Center for the Study of Asian American Health, NYU School of Medicine. Community Health Needs & Resource Assessment An exploratory study of South Asians in NYC. 2009.

58. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health 39. *Annu Rev Public Health*. 1998; 19(0163-7525):173–202. [PubMed: 9611617]
59. Becker, A.; Israel, B.; Allen, A. Strategies and techniques for effective group process in cbpr partnerships. In: Israel, B.; Eng, E.; Schultz, A.; Parker, E., editors. *Methods in community-based participatory research for health*. San Francisco: Jossey-Bass; 0095
60. Summerfield D. A critique of seven assumptions behind psychological trauma programmes in war-affected areas. *Soc Sci Med*. 1999 May; 48(10):1449–1462. [PubMed: 10369444]
61. Patel V, Pednekar S, Weiss H, Rodrigues M, Barros P, Nayak B, et al. Why do women complain of vaginal discharge? A population survey of infectious and psychosocial risk factors in a South Asian community 9. *Int J Epidemiol*. 2005 Aug; 34(0300-5771; 4):853–862. [PubMed: 15833795]
62. Patel V, Simunyu E, Gwanzura F, Lewis G, Mann A. The Shona Symptom Questionnaire: the development of an indigenous measure of common mental disorders in Harare. *Acta Psychiatr Scand*. 1997 Jun; 95(6):469–475. [PubMed: 9242841]
63. Miller KE, Omidian P, Quraishy AS, Quraishy N, Nasiry MN, Nasiry S, et al. The Afghan symptom checklist: a culturally grounded approach to mental health assessment in a conflict zone. *Am J Orthopsychiatry*. 2006 Oct; 76(4):423–433. [PubMed: 17209710]
64. Patel VV, Rajpathak S, Karasz A. Bangladeshi Immigrants in New York City: A Community Based Health Needs Assessment of a Hard to Reach Population. *J Immigr Minor Health*. 2011 Nov 25.
65. New York City Department of Health and Mental Hygiene. [Accessed 10/15, 2010] Epiquery: NYC Interactive Health Data System - Community Health Survey 2008-2009. 2010. Available at: <http://nyc.gov/health/epiquery>
66. Kroenke K, Spitzer RL. The PHQ-9: A new depression diagnostic and severity measure. *Psychiatric Annals*. 2002; 32(9):1–7.
67. Yu X, Stewart SM, Wong PT, Lam TH. Screening for depression with the Patient Health Questionnaire-2 (PHQ-2) among the general population in Hong Kong. *J Affect Disord*. 2011 Nov; 134(1-3):444–447. [PubMed: 21665288]
68. Arroll B, Goodyear-Smith F, Crengle S, Gunn J, Kerse N, Fishman T, et al. Validation of PHQ-2 and PHQ-9 to screen for major depression in the primary care population. *Ann Fam Med*. 2010 Jul-Aug; 8(4):348–353. [PubMed: 20644190]
69. Coyne JC, Thombs BD, Mitchell AJ. PHQ-9 and PHQ-2 in Western Kenya. *J Gen Intern Med*. 2009 Jul; 24(7):890. author reply 891. [PubMed: 19396499]
70. de Lima Osorio F, Vilela Mendes A, Crippa JA, Loureiro SR. Study of the discriminative validity of the PHQ-9 and PHQ-2 in a sample of Brazilian women in the context of primary health care. *Perspect Psychiatr Care*. 2009 Jul; 45(3):216–227. [PubMed: 19566694]
71. Karasz A, Mckinley P. Cultural differences in conceptual models of fatigue: A comparative study. *Journal of Health Psychology*. 2006 in press.
72. Mumford D, Bavington J, Bhatnagar K, Hussain Y, Mirza S, Naraghi M. The Bradford Somatic Inventory: A multi-ethnic inventory of somatic symptoms reported by anxious and depressed patients in Britain and the Indo-Pakistan subcontinent. *British Journal of Psychiatry*. 1991; 158:379–386. [PubMed: 2036538]
73. Mumford DB. The 'Dhat syndrome': a culturally determined symptom of depression? *Acta Psychiatr Scand*. 1996 Sep; 94(0001-690; 3):163–167. [PubMed: 8891081]

Figure 1.
Flow of survey respondents.

Table 1

South Asian Tension Scale

“Over the past 2 weeks, how often have you been bothered by any of these problems:”

	Not at all	Several Days	More than half the days	Almost every day	Don't Know
1. Feeling sad, feeling like crying, lonely	1	2	3	4	
2. Feeling a loss of appetite, nausea, stomach pain	1	2	3	4	
3. Trouble concentrating, loss of memory	1	2	3	4	
4. Feeling angry or frustrated	1	2	3	4	
5. Insomnia	1	2	3	4	
6. Feeling cold in the body (not due to weather)	1	2	3	4	
7. Feeling you would like to run away or escape	1	2	3	4	
8. Headaches or pain in your eyes	1	2	3	4	
9. Feeling anxious or afraid	1	2	3	4	
10. Feeling tired or a lack of energy	1	2	3	4	
11. Feeling helpless and unsupported	1	2	3	4	
12. Feelings of shakiness	1	2	3	4	
13. Sexual problems	1	2	3	4	
14. Feeling you want to be alone	1	2	3	4	
15. Problems with your periods	1	2	3	4	
16. Pains in your arms, legs, or other parts of your body	1	2	3	4	
17. Feeling homesick or missing family	1	2	3	4	
18. Feeling hot in parts of your body (not due to weather)	1	2	3	4	
19. Vaginal discharge	1	2	3	4	
20. Feeling dizzy	1	2	3	4	
21. Pain or heaviness in your chest, heart palpitations	1	2	3	4	
22. Feeling a loss of control of your hands or feet	1	2	3	4	
23. Breathlessness	1	2	3	4	
	Not at all	Some	A lot	Don't Know	
24. Your hair turning white or falling out	1	2	3		

Table 2**Characteristics of respondents**

	Mean (n)	SD (±)
Age	35.3 (162)	9.33
Years in U.S. (mean)	5.5 (147)	4.7
Mean household size	4.4	1.3
Education	<u>Proportion (n)</u>	
Less than High School	35.8% (58)	
H.S. graduate or equivalent	21% (34)	
Some College	19.7% (32)	
College graduate or more	23.5% (38)	
Comfortable using English	9.3% (15)	
Percent of Federal Poverty Level		
<100%	54.6% (47)	
101-200%	37.2% (32)	
201-300%	4.7% (4)	
>300%	4.4% (3)	
Unknown	46.9% (76)	
Marital Status – married	100% (162)	
Employment Status		
Employed	18.5% (30)	
Housewife	78.4% (127)	
Student/Retired	2.5% (4)	
Looking for a job	0.6% (1)	
Health Insurance		
Insured	91.6% (150)	
Medicaid	77.8% (127)	
Employer-based	5.4% (9)	
Medicare or other	8.6% (14)	
No insurance	6.3% (10)	
No Response	1.2% (2)	
Health Indicators		
Diabetes (Type 2)	10.5% (17)	
Hypertension	19.1% (31)	
Hyperlipidemia	25.3% (41)	

Table 3

Bivariate analysis of the Tension Scale and PHQ-2 with health indicators.

	Tension Scale	PHQ-2
PHQ-2	0.479 [#]	---
Age	0.240 [§]	0.161 [*]
Education	-0.224 [§]	-0.131
Self-rated Health	-0.271 [§]	-0.231 [§]
ER Visit in past 6 months	0.240 [§]	0.045
Seen a Physician in past year	-0.185 [*]	-0.176 [*]
Hypercholesterolemia	-0.258 [§]	-0.174 [*]
Hypertension	0.171 [*]	0.041
Diabetes	-0.149	
Perceived quality of diet	-0.249 [§]	-0.138

Values reported are Pearson's correlation coefficients.

*
p<.05,

§
p<.001

p<.0001