



Original article

# Recent advances in cross-cultural measurement in psychiatric epidemiology: utilizing ‘what matters most’ to identify culture-specific aspects of stigma

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## Abstract

**Background:** While stigma measurement across cultures has assumed growing importance in psychiatric epidemiology, it is unknown to what extent concepts arising from culture have been incorporated. We utilize a formulation of culture—as the everyday interactions that ‘matter most’ to individuals within a cultural group—to identify culturally-specific stigma dynamics relevant to measurement.

**Methods:** A systematic literature review from January 1990 to September 2012 was conducted using PsycINFO, Medline and Google Scholar to identify articles studying: (i) mental health stigma-related concepts; (ii)  $\geq 1$  non-Western European cultural group. From 5292 abstracts, 196 empirical articles were located.

**Results:** The vast majority of studies (77%) utilized adaptations of existing Western-developed stigma measures to new cultural groups. Extremely few studies (2.0%) featured quantitative stigma measures derived within a non-Western European cultural group. A sizeable amount (16.8%) of studies employed qualitative methods to identify culture-specific stigma processes. The ‘what matters most’ perspective identified cultural ideals of the everyday activities that comprise ‘personhood’ of ‘preserving lineage’ among specific Asian groups, ‘fighting hard to overcome problems and taking advantage of immigration opportunities’ among specific Latino-American groups, and ‘establishing trust among religious institutions due to institutional discrimination’ among African-American groups. These essential cultural interactions shaped culture-specific stigma manifestations. Mixed method studies (3.6%) corroborated these qualitative results.

**Conclusion:** Quantitatively-derived, culturally-specific stigma measures were lacking. Further, the vast majority of qualitative studies on stigma were conducted without using stigma-specific frameworks. We propose the 'what matters most' approach to address this key issue in future research.

**Key words:** Culture, stigma, measurement, scales, psychometric, literature review

#### Key Messages

- The vast majority of studies (77%) utilized adaptations of existing Western-developed stigma measures to new cultural groups, which are not designed to assess culture-specific forms of stigma.
- Very few studies (2.0%) featured quantitative stigma measures derived within a non-Western European cultural group, in which emic aspects of stigma were quantitatively assessed and operationalized.
- The vast majority of qualitative studies (81.8%) examining cultural effects upon mental illness stigma used generic qualitative approaches that were primarily inductive and did not incorporate theoretical stigma frameworks.
- We propose the 'what matters most' framework as a stigma-based, theoretically-driven approach to identify those aspects of stigma that threaten the culturally-defined capacities essential for 'personhood', which can then be operationalized and tested to predict stigma-related outcomes.

## Introduction

Development of approaches to reduce mental illness stigma constitutes a research priority for global mental health.<sup>1</sup> Whereas culture has been central to determining which characteristics are stigmatized in different groups and at different times,<sup>2-6</sup> it is unknown to what extent concepts arising from culture have been incorporated into measurement. Several comprehensive reviews of mental illness stigma measures exist,<sup>7-9</sup> but these do not systematically account for the influence of emic, or culturally-specific, concepts on measurement. The sole review of culture and mental illness that we are aware of,<sup>10</sup> while constituting an advance, is an unsystematic review and formulates culture from a primarily psychological perspective. Accordingly, this paper assesses current measurements of the cultural aspects of stigma via a systematic review of the literature based on an anthropological and epidemiological perspective. More accurate assessment of stigma's variation across cultures is essential to guide anti-stigma programmes and to promote social integration for people with mental disorders.

Standard approaches to measuring stigma across cultures typically consist of one of two forms. In the first, an instrument is psychometrically validated in a Western culture (typically the USA, UK or Australia) with people of Western European descent, translated with little or no modification into another cultural context, and then psychometrically evaluated. An example of this approach is

Link's Devaluation-Discrimination Scale (developed in the USA), which has been adapted to other cultures.<sup>11-12</sup> A second approach is when a measure is developed across multiple contexts, but a composite measure is developed to represent 'universal' aspects of stigma across contexts. One such example is the DISC-12 (Discrimination and Stigma Scale)<sup>2</sup> which was developed by interviewing consumers in 27 countries to assess common types of discrimination. These approaches have notable strengths, including enhancing scale reliability, generalizability and comparability across contexts.<sup>13</sup> However, one inadvertent consequence of these approaches is their elimination of stigma's culture-specific aspects.

While methods for reviewing qualitative research in a systematic way are still emerging, qualitative research places emphasis on contextualizing the phenomena of study.<sup>14</sup> Yet studies vary in the extent to which they incorporate cultural and structural influences in their analyses.<sup>15</sup> Some relatively straightforward studies organize data into related areas to construct 'descriptive' themes.<sup>16</sup> Other studies more thoroughly incorporate the general sociocultural context by integrating the role of cultural history and values and their interaction with mental illness stigma.<sup>14</sup> The value in these studies may lie in their capacity to go beyond simple summarization of the data to generate new interpretive explanations of how culture shapes stigma.<sup>15</sup>

We highlight such a promising theoretical framework to aid in identifying how culture-specific constructs determine

the most acutely felt effects of stigma. Unlike a focus upon general ‘shared beliefs and values’<sup>10</sup> and the primarily inductive theoretical qualitative approaches described above, this theory was derived to account for how cultural influences impact upon stigma specifically. Accordingly, Yang *et al.*<sup>17</sup> have proposed that assessment of cultural context via ‘moral experience’—which refers to that register of everyday life and practical engagement that defines ‘what matters most’ for ordinary men and women and ‘full status’ within a cultural group<sup>18</sup>—is key to understanding contextual effects on stigma. To engage in activities that ‘matter most’ is to certify an individual as having full standing within a cultural group. What is central is that these activities can be empirically identified and operationalized. Rather than simply relying upon asking people ‘What do you value?’, ‘what matters most’ is also observed by examining everyday, pragmatic interactions, or ‘What do you do?’ As a result, Yang *et al.*<sup>17</sup> propose that culture affects stigma by threatening an actor’s capacity to participate in the activities that determine ‘what matters most’ (or ‘personhood’) within a cultural context. For example, because the perpetuation of one’s lineage is a core aspect of what is valued most within Chinese cultures,<sup>19</sup> stigma is seen to most powerfully attack one’s ability to extend one’s lineage in these contexts.<sup>20</sup> This formulation is thus especially useful to cross-cultural measurement by identifying everyday lived activities that are culture-specific and closely shape stigma. These cultural dynamics, once identified, might also subsequently be operationalized into quantitative survey items and tested for their ability to predict other stigma-related outcomes (such as depression—see below).

We conducted a literature review to systematically assess how measures derived within non-Western European cultural groups incorporate culture-specific constructs. We focused on systematically evaluating the qualitative stigma literature to identify new, culturally-relevant constructs that might contribute to stigma measurement, and the use of stigma theory in the identification of these constructs. Such a review provides an assessment of to what extent researchers have incorporated cultural concepts, the stigma theories used (if any) and to what degree these cultural ideas have been implemented in measurement.

## Methods

To ensure systematic assessment, we followed a standard protocol adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist.<sup>21</sup>

As part of a study funded by the California Mental Health Services Authority, a literature review was

conducted in two stages to identify studies relevant to measuring culturally-focused constructs of mental illness stigma. In the first stage, an initial set of abstracts was identified in PsycINFO, Medline, and Google Scholar for relevant articles published between January 1990 and September 2012. Search terms were kept purposefully broad to cast a broad net and, for example, to find relevant studies in which ‘stigma’ was not mentioned in the title or abstract. The use of Google Scholar ensured that papers from disciplines such as anthropology and sociology were included. For both PsycINFO and Medline, search keywords included broad key terms of (*mental illness* OR *mental disorder*) AND (*stigma*). In PsycINFO, the search word (*mental illness*) included broad key terms of *anxiety disorders*, *affective disorders*, and *psychosis*, each of which represented multiple distinct disorders or related terms (see Appendix, available at *IJE* online, for complete search terms). Likewise, the search word of (*stigma*) included key terms of (*attitudes* OR *labeling* OR *prejudice* OR *social acceptance* OR *social approval* OR *social discrimination* OR *social perception* OR *stereotyped attitudes*). In Medline, the search word (*mental disorder*) included broad terms of *adjustment disorders* OR *anxiety disorders* OR *eating disorders* OR *impulse disorders* OR *mood disorders* OR *neurotic disorders* OR *schizophrenia*, each of which represented multiple distinct related terms (see Appendix, available at *IJE* online). (*Stigma*) included related terms of (*prejudice* OR *social stigma* OR *stereotyping*). Google Scholar search terms were (*stigma* AND *mental illness*) AND (*culture* OR *race* OR *minority* OR *ethnicity* OR *anthropology* OR *qualitative*). Based on the primary research team’s language fluency and to maintain systematic inclusion/exclusion criteria, only articles in peer-reviewed English language journals were retained; editorials, comments, letters and dissertations were excluded. A total of 5292 abstracts were located: 1527 abstracts from PsycINFO, 942 from Medline and 2823 from Google Scholar. From these abstracts, empirical research articles (qualitative or quantitative) concerning cross-cultural aspects of stigma were selected based on study of: (i) one or more mental health stigma-related concepts as defined by prominent stigma theorizations<sup>22–25</sup> and (ii) one or more non-Western European racial, ethnic or cultural group. Each abstract was screened by two independent master’s level reviewers, with disagreements resolved via discussion with the research coordinator. This process yielded 179 empirical articles. The primary reason for exclusion was duplication of articles. Seventeen additional articles resulted from examining the reference lists of identified articles and conferring with stigma researchers, yielding 196 articles in total.

In the second stage, as an initial step, 20 randomly selected articles were examined by the first author who coded content present in the articles to generate categories of: (i) stigma type; (ii) region of study; (iii) ethnic/cultural group; (iv) specific mental illness examined; and (v) how stigma was measured cross-culturally. The full database of 196 articles was then coded independently by two reviewers using these five categories. Disagreement between reviewers was resolved through group consensus. First, 'stigma type' was classified as: (a) public stigma; (b) self-stigma; (c) affiliate stigma; and (d) structural stigma (see Table 1 for definitions). Second, 'region of study', organized primarily by geographical continent, was classified. Third, specific 'ethnic/cultural group' was categorized. Fourth, classifications to capture the specific mental illness examined were undertaken. Fifth, 'how stigma was measured cross-culturally' was classified as: (a) adaptation of existing Western-developed stigma measure to new cultural group; (b) new, quantitatively-derived stigma measure within non-Western European sample that captures emic processes; (c) qualitative study of stigma that illustrates emic processes within a non-Western European sample; and (d) mixed-methods (i.e., qualitative and quantitative) study of stigma that illustrates emic processes within a non-Western European sample. These classifications then became the basis of subsequent analyses probing the cultural dynamics of stigma and measurement approaches designed to capture those dynamics.

## Results

### Stigma type

Table 1 shows the number and overall percentage of each type of stigma investigated. Most of the research involved public stigma (74.5%), with another sizeable component involving self-stigma (41.8%). Affiliate stigma was relatively rare (9.2%), with studies of structural stigma even rarer (2%). A significant subset of studies (48.7%) assessed more than one type of stigma.

**Table 1.** Number and Percentage of Stigma Types Investigated

Stigma type	Definition	<i>n</i> <sup>a</sup>	%
Public	The process in which the general public stigmatizes individuals with mental illness and which consists of processes of stereotyping, prejudice, and discrimination	146	74.5
Self (internalized)	When an individual takes publicly acknowledged stereotypes held by society and applies them to him or herself	82	41.8
Affiliate	When stigma is experienced among those who are closely associated with labelled individuals	18	9.2
Structural	Institutional practices that work to the disadvantage of the stigmatized group or person	4	2.0

<sup>a</sup>Total *n* = 196; percentages do not add up to 100 because of use of more than one stigma type in studies.

### Region of study

The most common regions where studies took place were in North America (*n* = 90 or 45.9%) or Europe (*n* = 89 or 45.4%). A substantial proportion of research was conducted in Asia (*n* = 42 or 21.4%), followed by the Middle East (*n* = 20 or 10.2%). Relatively fewer studies took place in Eurasia (i.e. Australia and New Zealand; *n* = 8 or 4.0%) or Africa (*n* = 8 or 4.0%), with the fewest being conducted in South America (*n* = 3 or 1.5%).

### Ethnic/cultural group

The specific ethnic/cultural groups studied were classified. Within the USA, African American groups were most studied (*n* = 41 or 20.9%), followed by Latino groups (*n* = 36 or 18.3%), Asian/Pacific Islanders (*n* = 20 or 10.2%) and Native Americans (*n* = 3 or 1.5%). Although not the focus of our study, 37 studies (18.8%) within the USA also included people of Western-European descent (typically for comparison purposes). Internationally, Asian/Pacific Islanders were studied most frequently (*n* = 48 or 24.4%), followed by Middle Eastern groups (*n* = 15 or 7.6%) then African groups (*n* = 14 or 7.1%). Among international studies, 56 (28.6%) studies included people of Western-European descent.

### Mental illness addressed

Depression/dysthymia was most commonly studied (*n* = 89 or 45.4%), followed by schizophrenia/psychotic disorders (*n* = 81 or 41.3%) and general/non-specific mental illnesses (*n* = 78 or 39.7%). Bipolar disorders (*n* = 19 or 9.7%) and anxiety disorders (*n* = 18 or 9.2%) were next most studied. More seldom investigated were substance use disorders (*n* = 7 or 3.6%), affective disorders (*n* = 6 or 3.1%), post-traumatic stress disorder (*n* = 5 or 2.5%), attention-deficit/hyperactivity disorder (*n* = 3 or 1.5%) and somatic disorders (*n* = 2 or 1.0%).

### How stigma was measured cross-culturally

Because most stigma measures have traditionally been developed in Western countries among Western European

groups,<sup>8</sup> it is not surprising that the vast majority of studies ( $n = 151$  or 77.0%) utilized adaptations of existing Western-developed stigma measures to new cultural groups. Of note, these standardized measures are not designed to detect culture-specific forms of stigma. Because of their implications for cross-cultural stigma measurement, each of the remaining classifications from this category is reviewed in detail below. Within each category, we first review studies among (i) non-immigrant groups and (ii) immigrant groups.

#### Quantitatively-derived stigma measures that capture emic processes

Further corroborating the prior finding, only four studies (2.0%) featured quantitative stigma measures derived within a non-Western European cultural group. Table 2 summarizes these studies, describing the sampling, item generation (including an example of a culture-specific item), psychometric properties and culturally-specific aspects. These four studies represent diverse methods in which emic aspects of stigma might be quantitatively evaluated. Among non-immigrant groups, Tsang<sup>26</sup> developed a measure of public stigma using items from pre-existing measures augmented by items derived from interviews with health professionals and individuals with mental illness in Hong Kong, thus including several items appropriate to Chinese culture to assess impact of mental illness upon families. A second measure, also derived in Hong Kong,<sup>27</sup> assessed the impact of mental illness stigma upon family members and specifically incorporated assessment of 'face loss' from the caregiver (or 'affiliate') perspective. Among immigrant groups, a measure assessed the different aspects of shame (external shame, internal shame and reflective shame<sup>28</sup>) that may be relevant to a South Asian population. In particular, this measure's assessment of reflected shame (i.e. believing that one can shame the family/community or that others can bring shame to the self) appears especially salient. Another measure, derived from qualitative analyses of antidepressant stigma concerns exhibited by Latinos in the USA,<sup>29</sup> evaluated attitudes specific to Latinos that psychiatric medication use is equated with illicit drug dependence, thus leading to culture-specific forms of stigma.

#### Qualitative studies of stigma that illustrate emic processes

Whereas only four studies offer quantitative development of emic stigma measures, 33 (16.8%) studies of qualitative investigations of emic stigma processes were identified. These qualitative studies offer a rich resource by which to develop new culture-specific stigma measures. We first classified these qualitative studies into cultural groupings of: (i) Asian; (ii) Latino; (iii) African American (USA-born individuals of African descent); or (iv) Other (including

Africans from continental Africa). We review African Americans separately from Africans in view of their long history within the USA and their distinct circumstances of historical discrimination.<sup>30</sup> We further group the qualitative analyses used into one of three broad categories according to the typology of qualitative studies described earlier (i.e. the extent to which cultural influences are incorporated<sup>14–16</sup>): (a) studies which primarily construct 'descriptive' themes summarizing main topics; (b) studies which incorporate the role of cultural history and values; (c) studies which interpret stigma in terms of cultural ideals of the everyday activities that comprise 'personhood' and how mental illness stigma challenges these ideals (i.e. 'what matters most') (Table 3). Studies were selected for the 'what matters most' category if the same concepts were recognized, even if identical words were not used (i.e. conceptual 'translation'<sup>16</sup>). A brief description of qualitative methodology used is followed by a narrative analysis of the main findings within each cultural group, with a focus upon cultural constructs that might be operationalized for future measurement.

#### Qualitative Methodology

Examining the qualitative methodologies used, only 2 of the 33 qualitative studies used an explicit stigma framework<sup>31,32</sup> to guide analyses. An additional four studies examined how stigma impacted either daily lives or social roles,<sup>33,34</sup> ethnic group membership,<sup>35</sup> or 'what matters most'.<sup>36</sup> The remaining 27/33 studies utilized primarily inductive, or other (e.g. explanatory model) frameworks in analysing stigma.

#### Narrative Analysis of Main Cultural Findings

*Asian Groups.* Examining the main cultural findings, among non-immigrant Asian groups, any emotional weakness was seen as taboo among American Samoa.<sup>37</sup> Studies that incorporated cultural norms and values indicated that 'face' is a crucial construct that shapes stigma among Taiwanese caregivers<sup>38</sup> and Chinese carers in Hong Kong.<sup>39</sup> Further, mental illness was seen as a reflection of bad karma linked to past misdeeds among mothers in Hong Kong.<sup>40</sup> Among immigrant Asian groups, thematic analyses indicated that mental illness problems seriously impacted on the reputation of Chinese and Tamil families in Canada,<sup>41</sup> as well as Filipinas in New Zealand.<sup>42</sup> Studies that incorporated cultural norms and values demonstrate that loss of 'face' continued to impact stigma among Asian immigrants, including Vietnamese Americans<sup>43</sup> and Chinese caregivers in the UK.<sup>44</sup> Further, mental illness indicated bad karma linked to past misdeeds (among Chinese, Pakistani and Indian groups in Scotland<sup>32</sup>), which elicited shame because individuals



**Table 2a.** Quantitative stigma measures that capture emic processes: Non-immigrant populations

Author, year	Sample	Item generation	Psychometric properties	Culture-specific domains
Tsang <i>et al.</i> , (2003)	1007 relatives and friends of primary and secondary students—Hong Kong	Gathered by review of existing scales and literature; included Opinions About Mental Illness Scale (Cohen and Struning, 1962) <sup>1</sup> and Attitudes Towards Disabled Persons Scale (Yuker and Block, 1960). <sup>2</sup> Review of literature on attitudes and family burden suggested additional items. Five rehabilitation health professionals and three people with MI were interviewed and invited to suggest new items	Eight factors—50.6% of total variance: hostility; aberrant; openness; acceptance; rights; misgivings; accommodation; and resources. Culture-specific item: 'In favour of more support for families'	Scale developed with special reference to issues that affected the burden on family member of MH provision to consumers
Mak <i>et al.</i> , (2008)	210 caregivers of people with intellectual disability and 108 caregivers of people with MI—Hong Kong	Based on literature review of associative stigma and focus group discussion with caregivers, a 22-item scale developed to measure caregivers' internalization of stigma. Scale items measured cognitive, affective and behavioural components of affiliate stigma	Reliability = 0.93; one factor model = 49.03% total variance; validity—predicts subjective caregiver burden. Culture-specific item: 'Having a family member with MI makes me lose face'	Affiliate stigma may be particularly salient among Chinese people given their cultural beliefs towards MI and cultural value of 'face' concern

MH, mental health; MI, mental illness.

<sup>1</sup>Cohen J, Struening EL. Opinions about mental illness in the personnel of two large mental hospitals. *J Abnorm Soc Psychol* 1962;64:349.

<sup>2</sup>Yuker HE, Block JR, Campbell WJ. *A Scale to Measure Attitudes Toward Disabled Persons*. New York: Human Resources Center, 1960.

**Table 2b.** Quantitative stigma measures that capture emic processes: Immigrant populations

Author, year	Sample	Item generation	Psychometric properties	Culture-specific domains
Gilbert <i>et al.</i> , (2007)	186 female university undergraduate students; 89 classified as South Asian—UK	Based on literature review of shame-focused attitudes, the Attitudes Towards Mental Health Problems Scale, a 35-item scale, was developed to measure internal and external shame and reflected shame	Reliability = .85–0.97; validity—Asians show higher external shame and reflected shame, but not internal shame. Culture-specific item (on reflected shame): 'My family would lose status in the community'	Assesses reflected shame (believing that one can bring shame to family/community i.e., shame one can bring to other or other can bring to the self)
Interian <i>et al.</i> , (2010)	200 low-income Latinos screened for depression; completed four stigma measures at two time points (25- and 30-month follow up)—USA	The Latino Scale for Antidepressant Stigma formulated from qualitative analysis of anti-depressant stigma concerns of Latino sample. Contains seven items with stigma-related statements pertaining to use of antidepressants	Reliability = 0.66–0.69; factor analysis shows unidimensionality. Clinically significant reduction in utilization rates (18–40%)—stigma associated with antidepressant usage. Culture-specific item: 'People who take prescribed medication for depression are affected as if they were on drugs'	Evaluates Latino-specific stigma towards anti-depressant use

should be able to control their feelings in social interactions.<sup>45</sup> These impacts led to impaired opportunities to marry for the person and the entire family network among several Asian immigrant groups.<sup>32,46</sup> Interpretation of the above findings is facilitated by 'what matters most'<sup>36</sup> which provides a theoretical framework to interpret stigma's impacts in terms of cultural ideals of the daily capaci-

ties necessary for 'personhood', thus providing a framework for organizing the above findings. For example, Chinese groups are seen to value perpetuation of the lineage, both in honouring ancestors and in continuing the family line into perpetuity. Chinese families in traditional settings require 'face' to participate in social exchange networks that enable the fulfillment of crucial life

**Table 3.** Qualitative studies of stigma that illustrate emic processes.

Author, year	Sample	Qualitative method	Qualitative analysis	Culture-specific implication
Asian—non-immigrant populations				
Thematic				
Held <i>et al.</i> , (2010)	39 diabetes patients and 13 healthcare staff—American Samoa	6 focus groups w/ patients and 13 interviews w/ staff	Passages related to depressive symptoms coded by themes	Depression considered taboo, embarrassing or indication that someone is crazy. MI is not acceptable, and considered something they can hide
Cultural norms/values				
Wang <i>et al.</i> , (2011)	10 Taiwanese patients w/ severe MI—Taiwan	Semi-structured interviews	Extraction of emerging themes	Stigma influences social and family domains due to Chinese 'face', culture and emphasis on familism. Thus, consumer's family members feel 'face is lost' once MI known to outsiders
Wong <i>et al.</i> , (2007)	58 Chinese caregivers of patients w/ early psychosis—Hong Kong	In-depth, semi-structured interviews	Content analyses of help-seeking framework	To avoid losing face in public, consumers w/ MI and family members would not actively seek help from others, particularly not from formal professionals
Pun <i>et al.</i> , (2004)	22 Chinese mothers of children w/ behavioural/emotional difficulties—Hong Kong	In-depth interviews	Thematic analysis based upon ecological systems model	Within Chinese culture, achievement of the child is related to worth of the parents; bad or inadequate performance by child may be attributable to mother. Traditionally-minded people would attribute impairment to misdeed done by parents or ancestors
Asian—immigrant populations				
Thematic				
Sadavoy <i>et al.</i> , (2004)	Chinese & Tamil seniors, families and MH providers—Canada	17 focus groups	Grounded theory—coding materials, deriving themes and categories	Seniors and families believe MI problems seriously impair reputation of family which leads to help-seeking avoidance. Privacy especially a concern for small, close knit Tamil community
Thompson <i>et al.</i> , (2002)	Filipina women—Australia	7 focus groups and 129 in-depth interviews; follow-up—8 focus groups and 74 interviews	Coding for major themes using content analysis	'Mental' illness highly stigmatized and associated w/ weakness in personality. Filipinas talked of fear associated w/ psychiatric services and spoiling family's reputation
Cultural norms/values				
Fancher <i>et al.</i> , (2010)	11 Vietnamese American patients w/ MI or had family/friends w/ MI—US	Semi-structured interviews	Grounded theory—predominant themes and patterns categorized	MI results in loss of face for consumers and families as MI is seen as reflection of poor moral character, spiritual weakness or improper upbringing by family
Koo <i>et al.</i> , (2012)	14 Chinese British carers of unipolar and bipolar depression—UK	Semi-structured interviews	Content indexing technique—major themes identified, generating thematic narratives	Respondents' embarrassment and shame strongly connected w/ 'face loss', or losing one's identity. In collectivist communities, individual identity derives from group membership; if stigma operates by denying the individual status within the group, then identity is adversely affected
Knifton <i>et al.</i> , (2012)	87 participants in Pakistani, Indian and Chinese heritage communities—Scotland	Focus groups	Grounded theory—identification of key themes and categories with initial framework of 'beliefs about mental illness', 'stigma' and 'national anti-stigma campaign'	Both Chinese and Hindu groups discussed karma linked to blame. One explanation framed MH problems as punishment from God, caused by spirits or jinn. Respondents described examples of how extended family structures and focus on marriage magnify the impact of stigma
Lin <i>et al.</i> , (2012)	29 highly acculturated Chinese American patients w/ severe MI—USA	Semi-structured interviews	Identification of major themes	Participants described feelings of failure and shame when unable to meet high expectations of families. Believed that, as being Chinese, one should be in control of feelings, not overreact or act out in public

(Continued)

Table 3. Continued

Author, year	Sample	Qualitative method	Qualitative analysis	Culture-specific implication
Conrad <i>et al.</i> , (2005)	23 MH providers (Caucasian, Asian Indian, Black American) and 20 MH records of depressed patients—USA	Individual interviews w/ MH providers and review of 20 patients' MH records	Identification of emerging themes and patterns to create categories	MI highly stigmatized and generally hidden to safeguard children's marriage arrangements. Stigma also tied to religious belief in suffering as punishment for past deeds
What matters most				
Yang <i>et al.</i> , (2014)	50 Chinese immigrants w/ MI—USA	Semi-structured interviews	Deepening knowledge of 'what matters most' and stigma framework, followed by identifying and expanding themes to form concepts	'What matters most' is perpetuation of lineage through work. Working represents opportunity to demonstrate moral cultivation by repaying kinship obligations. Also provides means to bring prestige to kin group and honour lineage by finding spouse and obtaining USA residency
Latino—immigrant populations				
Cultural norms/values				
Guarnaccia <i>et al.</i> , (1992)	45 Hispanic families of people w/ severe MI (30 Puerto Rican, 6 Cuban, 9 other Hispanic)—USA	In-depth interviews	Coding of core themes	Use of cultural category of "nervios" increased rapport and decreased stigma of using MH services
Pincay <i>et al.</i> , (2007)	94 Latinos (Puerto Rican, Dominican, Mexican and Cuban) w/ depression—USA	12 focus groups	Content analysis of major emerging themes	Respondents believe medication signals long-term disability and inability to care for self, also poses threat of addiction. Beliefs arise from community models of other substances like caffeine and nicotine
Cabassa <i>et al.</i> , (2011)	32 Latinos (Mexico, Guatemala, El Salvador) in adult school programmes—USA	4 focus groups	Content analysis to generate analytical memos and major themes	Respondents viewed depression and MH treatment as result of personal weakness. Believed antidepressant medication to be addictive and expressed fears of dependency, loss of control, physical harm
Cabassa <i>et al.</i> , (2008)	19 Hispanics w/ diabetes and depression selected from RCT—USA	4 focus groups and 10 in-depth, semi-structured interviews	Grounded theory—coding of emergent themes and analytical memos, consensus, co-occurrence, comparison	Stigma attached to antidepressants; believe medications only used to treat crazy individuals (locos) w/ serious MH problems, and afraid medication could damage brain
Willing <i>et al.</i> , (2006)	42 LGBT respondents (16 Hispanic, 14 American Indian, 8 White, 1 other) w/ MI—USA	Semi-structured interviews; follow-up w/ 14 individuals at 6 months and 1 year	Open coding to discover themes, followed by identification of repeated themes	'We fix ourselves here.' Attitude applied to MI, frequently portrayed as problems one could 'will away' through 'self reliance' and 'hard work'. Common notion of MI as character defect or laziness
What matters most				
Interian <i>et al.</i> , (2007)	30 Latino participants (Puerto Rican, Dominican Republican and Mexican) outpatients receiving antidepressants—USA	6 focus groups	Grounded theory—identify themes related to stigma and anti-depressant use	Culture emphasizes resilience and ability to cope without antidepressants. Self-perceived cultural characteristics—being trabajadores (hard-working), luchadores (people who fight against problems) and aprovechadores (people who take advantage) of opportunities—are at odds w/ perceived negative attributes of taking antidepressants
Collins <i>et al.</i> , (2008)	24 Latina American women w/ severe MI—USA	Semi-structured interviews	Modified grounded theory with analytical focus on how stigma of mental illness related to ethnic minority membership and sexuality; identify emergent themes via open coding followed by categorization	Latina women strive to be 'proper women'—get married, raise children, have career, maintain home—achieve goals they immigrated for and others expect as part of lives. MI places them at risk of rejection or derision; inability to have children/care for them is a source of pain and disempowerment. Many identify as 'church ladies' as a means to cope

(Continued)



**Table 3.** Continued

Author, year	Sample	Qualitative method	Qualitative analysis	Culture-specific implication
African American—non-immigrant populations				
Thematic				
Hines-Martin <i>et al.</i> , (2003)	24 African American service users—USA	In-depth interviews	Identify common themes, patterns and categories	Respondents' hesitancy in revealing private thoughts and emotions comes from fear/mistrust of others' responses resulting from revealing MI; mistrust of others' concern. Among older adults, wariness of receiving services from professionals adds to distrust based on cultural differences
Joo <i>et al.</i> , (2011)	102 African American and European American adults aged 65 and older—USA	Semi-structured interviews	Identify themes to form categories related to counselling and psychotherapy	Stigma and added impact of wariness of receiving services from professionals adds to distrust based on cultural differences. Professionals seen as too 'straight,' impersonal and formal.
Cultural norms/values				
Franz <i>et al.</i> , (2010)	12 African American family members of first-episode psychosis—USA	In-depth interviews	Identify recurring categories and themes to develop framework informed by Modified Labelling Theory	Constructs of race, cultural mistrust, prejudice and healthcare access for minorities deserve mentioning. Inequalities engender cultural mistrust among African Americans, and has been shown to predict negative help-seeking attitudes
Alverson <i>et al.</i> , (2007)	25 inner-city participants (9 Caucasian, 6 African American, 10 Puerto Rican) w/ severe MI selected from RCT—USA	Participant observation	Identification of most common themes related to mental illness	'Privacy'/'family business'—pervasive aspect of folk ideology. Families of consumers treated symptoms as character issues, such as lazy, irresponsible or possessed. Consumers saw themselves as 'guinea pigs' being experimented w/ or controlled through 'all those damned pills'
Carpenter-Song <i>et al.</i> , (2010)	25 Patients w/ severe MI (6 African American, 10 Latino, 9 European American)—USA	Participant observation and extensive field notes	Identification of most common themes related to mental illness	MI considered to constitute private 'family business'; injunction not to 'air one's business' outside family. Dire social consequences—feared ridicule, disparagement and even retaliation—'they pick on you because they know you have something wrong w/ you'
Johnson <i>et al.</i> , (2009)	10 African American females w/ panic disorder—USA	3 focus groups	Identify themes to form codes which were incorporated as probes for following focus groups	Emotional symptoms often perceived by social network as sign of insufficient faith. Fear of being stigmatized and perceived as personally or spiritually weak are among common reasons to isolate self
What matters most				
Kranke <i>et al.</i> , (2012)	17 African American adolescents diagnosed w/ MI and taking psychotropic medication—USA	Semi-structured interviews	Deepening knowledge of a priori themes of self-reliance, cultural beliefs, familial beliefs and faith beliefs; followed by identifying and sorting emerging themes	Familial beliefs and cultural norms encourage self-reliance and strong ties to faith. MH counselling often sought from ministers/clergy due to belief in prayer; MI seen as curable, attributed to religious intervention. Negative views towards medication; also mistrust and concern as MH needs not adequately addressed within medical establishment
African—non-immigrant populations				
Cultural values				
Kapungwe <i>et al.</i> , (2010)	65 participants from health care, government, and academia from 3 districts—Zambia	6 focus groups and 50 semi-structured interviews	Grounded theory—identify categories, themes and patterns	Respondents understand MI as 'bewitchment', 'Satanism' and 'evil spirits'. Common beliefs that individual has done wrong in community; as result, person or member of family is bewitched. Like an omen they are punished through MI.

(Continued)

Table 3. Continued

Author, year	Sample	Qualitative method	Qualitative analysis	Culture-specific implication
What matters most				
Read <i>et al.</i> , (2009)	25 patients, 31 carers, 3 traditional healers, 4 pastors, 3 imams, 1 mallam (67 total)—Ghana	Observation, conversation, semi-structured interviews and focus groups	Grounded theory—identify recurring themes, including impact of mental illness on the individual's day-to-day life and social roles	Culture emphasizes sociality, reciprocity and responsibility, and individualism. Stigma of MI as unpredictable, irrational, and violent directly opposes social ideals. Responsibility for others, such as parenting, is valued as the mark of adulthood. Failure to achieve markers of adulthood/responsibility is analogous to that of child
African—immigrant populations				
Cultural values				
Whittaker <i>et al.</i> , (2005)	5 Somali (Black African Muslim) refugee and asylum-seeking women—USA	Individual and group interviews	Identify themes and organize into higher-order themes	Somali participants struggled w/ being 'too westernized'; described as cause for concern and result in label as 'mad'. Religion also strong force in participants' lives, promotes psychological well-being and provides guidance in difficult times. Qur'an as source of guidance in how to react, understand and cope w/ loss and difficulties
Germany—non-immigrant populations				
Cultural values				
Schulze <i>et al.</i> , (2003)	25 patients, 31 relatives, and 27 MH providers (83 total)—Germany	Focus groups	Identify categories to form coding scheme in the patient groups; coding system was then deductively used to code the relative and provider group data	Achievement and competitiveness seen as contributing to MH stigma; often people suffering from MI are not capable of meeting dominant criteria for recognition and integration. Performance demands and view that people w/ MI are not capable and have negative effect in labour market
Iran—non-immigrant populations				
Cultural values				
Dejman <i>et al.</i> , (2010)	38 men and 38 women; 4 focus groups for each of three ethnic groups: Fars, Turks and Kurds—Iran	12 focus groups	Coding scheme of illness, cause and help-seeking used; identify themes to create new codes and categories within each	Stigma associated w/ having soul distress. Illness described as a non-serious problem w/ nerves which, due to some recent external stressor in life, caused physical and soul problems
Albania—immigrant populations				
Cultural values				
Dow <i>et al.</i> , (2011)	12 Albanian immigrants—USA	In-depth, semi-structured interviews	Identify and compare categories and codes to derive main themes	Important not to discuss family business to protect family and save face. Beliefs originate from ancient code of Kanun. Family members have special obligations to uphold and maintain honour and reputation of family and are affected if one of own brings shame on the family
Soviet Union—immigrant populations				
Cultural values				
Polyakova <i>et al.</i> , (2006)	Soviet elder immigrants; 23 key informants and 10 general informants—USA	Participant observation, semi-structured interviews, follow-up interviews	Identify categories to derive emerging themes	MI viewed as lack of dusha (inner strength and moral character), viewed as disease of dusha (soul), and individual is perceived to be lacking moral character and self-control. Person w/ MI has lost their inner strength and moral character (dusha) and is beyond help

w/, with; MH, mental health; MI, mental illness; LGBT, Lesbian/Gay/Bisexual/Transgender; RCT, randomized controlled trial.

opportunities, including opportunities to work and finding a marriage partner. Moral cultivation, in the development of character reflected in the control of emotions during everyday interaction, was required to claim ‘face’. Accordingly, much of the qualitative findings about how stigma has culture-specific effects among many Chinese groups (and many associated Asian groups) can be organized and interpreted by how mental illness threatens these everyday lived values required for ‘personhood’.

*Latino Groups.* Among Latino groups, only studies among immigrant groups were found. Studies that incorporated cultural values indicated that lay interpretations of mental illness as the cultural idiom of ‘nervios’ led to decreased stigma among Latino American caregivers.<sup>47</sup> One consistent qualitative finding was that antidepressant medications were viewed as addictive, causing loss of control and physical harm. This perspective, which was modelled on community views of other addictive substances like nicotine,<sup>48</sup> was reported among Latino-American community members,<sup>49</sup> Latino-Americans with depression<sup>48</sup> and Latino-Americans with depression and diabetes.<sup>50</sup> Further, prevailing attitudes that one could ‘will away’ through self-reliance any mental health problems led to views of mental illness as indicative of laziness.<sup>51</sup> Framing these results within the culturally-defined core lived activities of individuals within Latino American local worlds further illuminated these findings. ‘What matters most’ in these cultural worlds—such as being *trabajadores* (hard-working), *luchadores* (a person who fights against problems) and *aprovechadores* (a person who takes advantage) of the opportunities provided in the USA<sup>52</sup>—emphasized being resilient and coping with life stressors without psychiatric medications. Taking medications and thus being categorized as *floja* (weak), *inutil* (useless) or *chiquitita* (small) violated this fundamental lived value of being a hard-working person who struggles to overcome problems, thus appearing to increase stigma. In a separate local world (i.e. Latina-American women living with severe mental illness in New York City), these women’s inability to fulfill the cultural ideals of being a ‘good girl’ or ‘proper woman’—i.e. being a good wife and mother, including taking on household responsibilities and educating the children—was thwarted by the disability brought on by mental illness.<sup>35</sup> Accordingly, being unable to have or care for children was a particularly powerful source of rejection and stigma.

*African-American Groups.* Among African American groups, thematic analyses indicated that respondents revealed hesitancy in disclosing private thoughts and emotions.<sup>53</sup> This tendency was compounded by distrust of receiving services from mental health professionals from

mainstream groups, such as among African American elders.<sup>54</sup> Studies that incorporated cultural values among African American groups further identified privacy or ‘family business’ as a pervasive aspect of folk ideology,<sup>55</sup> such that disclosing mental illness had dire social consequences.<sup>56</sup> In terms of mistrust towards health providers such as being ‘experimented with’ via medication,<sup>55</sup> these attitudes might be attributable in part to longstanding inequalities regarding healthcare access.<sup>31</sup> Yet another prominent cultural value was that of spirituality, whereby emotional symptoms were perceived as being a sign of insufficient faith and thereby spiritual weakness.<sup>57</sup> Cultural ideals of the everyday activities that define ‘personhood’ or ‘what matters most’ among many African American groups helped to organize the above stigma findings. Familial and cultural ideology encouraged self-reliance and strong ties to faith, whereby many ills were seen as curable by religious intervention rather than by medication use.<sup>34</sup> Because of historic institutional discrimination from public agencies,<sup>34</sup> trust or ‘personhood’ in many African American communities instead was established via everyday interactions among religious institutions—and when the individual’s and family’s reputation became threatened by disclosure of mental illness, intensified stigma results.

*Other Cultural Groups.* Among ‘Other’ cultural groups, we highlight one study in Africa, as this study incorporates concepts of ‘what matters most’ in its stigma analysis. This study examined psychiatric stigma in rural Ghana, and rather than emphasizing religious factors as in other studies of African groups,<sup>58,59</sup> observed that the social ideals of ‘personhood’ lay in taking responsibility for others, such as parenting children and contributing to the well-being of kin and wider community.<sup>33</sup> Stigma arose in this context because individuals with mental illness might fail to affirm ideals of reciprocity and responsibility, thus failing to achieve markers of adulthood and being accorded a ‘child-like’ status. Although not the focus of our review, we highlight one other study in Germany because of its potential to illustrate ‘what matters most’ within certain Western European groups.<sup>60</sup> Here people with mental illness experienced stigma most acutely because they might not exhibit the achievement or competitiveness needed for high-performing jobs that were central to societal recognition. Similar dynamics of competitiveness and productivity may exist and exacerbate stigma among certain people of Western-European descent in Western contexts.

#### Mixed-methods studies of stigma that illustrate emic processes

Seven (3.6%) studies combined qualitative and quantitative methods to assess stigma (Table 4). Because this paper

**Table 4a.** Mixed-methods studies of stigma that illustrate emic processes: Non-immigrant populations

Author, year	Sample	Qualitative analysis	Qualitative findings	Quantitative findings in support of qualitative findings
Murry <i>et al.</i> , (2011)	163 quantitative surveys and 21 qualitative interviews w/ African American rural women—USA	Grounded theory—identify recurring themes to form codes and coding system	Particularly concerned about ‘putting business in the street’. Church historically served as key source of strength for families, providing social support, offering guidance on childrearing, and a coping mechanism for managing and overcoming difficult life experiences	Most reports of perceived stigma reflect family-level concerns; 56% of caregivers concerned that community would likely find out if child received professional help and blame parents for child’s problems
Corrigan <i>et al.</i> , (2008), Corrigan <i>et al.</i> , (2010)	Qualitative interviews w/ 100 employers used to create Employer Perspective Scale, measuring employer perspectives about hiring people w/ health conditions (including MI); scale administered to 300 employers—Chicago, Beijing and Hong Kong	Coding of presence or absence of identified themes	Emphasis on familism in Chinese culture; people w/ disability suffer personal embarrassment and also bear responsibility for bringing shame to family lineage. Beijing employers less likely to endorse hiring people w/ disabilities compared w/ those from Chicago and HK	Confirmatory analysis—(i) Overall concern; (ii) overall assets; (iii) resources for employees; and (iv) resources for employers. Chicago employers blamed people w/ health conditions less often for onset/offset of disorders compared with Beijing and HK. Beijing endorsed offset responsibility less often than HK employers. Chicago employers less likely to endorse overall concerns and more likely to recognize assets
Lindsey <i>et al.</i> , (2010)	Quantitative surveys and interviews w/ 69 African American adolescent boys—USA	Identify themes and patterns to form categories and coding system	Crying as result of emotional pain might precipitate feelings of vulnerability and weakness; if conveyed among peers, potential for antagonism increases. Help-seeking for group bounded within contextual and systemic stressors, influences interactions w/ and unwillingness to connect w/ professionals	Stigma predicts depression symptoms. Social support buffers negative effects of stigma on depression
Johnson <i>et al.</i> , (2009)	Interviews w/ 246 Ugandan adults—compared explanatory models of community members (135) and practitioners (111)—Uganda	Utilizing an explanatory model framework, emerging themes were identified and elaborated upon to form a coding system	Psychotic depression thought to be caused by neglect of traditional rituals, breaking of taboos, or mixing African and Western belief systems	65% of respondents state that depressed person would feel embarrassed or shamed and face a negative response in the community, especially if he/she failed to meet responsibilities
Weiss <i>et al.</i> , (2000)	Interviews w/ 80 patients in Bangalore and 47 patients in the UK	Analysis of narrative responses	Cultural values associated w/ dharma—concept encompassing traditional norms of conduct. Reliance on social standing and social networks. Inability to fulfill family and social obligations associated w/ increased stigma. Focus on adverse impact of disclosure and importance of arranging marriages	None

prioritizes utilizing qualitative methods to document key processes through which cultural processes influence stigma, we presented quantitative findings when these contributed to interpretation of qualitative findings.<sup>61</sup> Examining the qualitative methodologies used, none of the

mixed-method studies used an explicit stigma framework or ‘what matters most’ concepts to guide analyses, instead primarily relying upon inductive frameworks. In most cases, the main cultural findings from the mixed-methods studies corroborated the cultural dynamics previously

**Table 4b.** Mixed-methods studies of stigma that illustrate emic processes: Immigrant populations

Arcia <i>et al.</i> , (2004)	Interviews w/ 63 Latina Caribbean mothers of children w/ symptoms of disruptive disorders—US	Review of cases by reference to 'anxiety' and identification of emerging themes; these themes were then reviewed with 'cultural informants'	Extended treatment is indication of inability to exert control over condition. Service use and/or continued medication use possibly strong indicators of illness and disability. High stigmatization likely key reason why population refuses medication	None
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w/, with; MH, mental health; MI, mental illness; US, USA; HK, Hong Kong.

identified in the qualitative studies. Among non-immigrant groups, in one qualitative study of employers in Beijing, Hong Kong and Chicago,<sup>62,63</sup> employers in Beijing were less likely to hire people with mental illness, ostensibly due to 'familism', where an individual's actions impacted on entire kin and social networks. These qualitative findings were used to create the 'Employer Perspective Scale' about hiring people with health conditions (including mental illnesses) which indicated more blaming attitudes among employers from Beijing and Hong Kong towards individuals with mental illness. A mixed-methods study of rural African American women reported qualitative findings that the Black Church has traditionally served as a key source of social support and, due to prevailing norms of self-reliance and privacy, that this group was particularly concerned about 'putting private business on the street'.<sup>61</sup> Corroborating quantitative findings showed that approximately half of respondents endorsed that parents would be blamed for the child's problem. Among African American male adolescents,<sup>64</sup> larger systemic stressors (i.e. negative interactions with police) made acceptance by family and peers even more central, and displaying emotional problems among peers led to stigma due to perceived weakness. These qualitative results were further supported by quantitative findings that social support buffered the negative effect of stigma on depression in these African American youth. Another mixed-methods study among community members in Uganda revealed qualitative themes of mental illness being caused by neglect of traditional rituals.<sup>65</sup> Corroborating quantitative findings included 65% of respondents reporting that a depressed person would face a negative community response. In a mixed-methods study of depressed patients among Indians in Bangalore,<sup>66</sup> qualitative results indicated that neglecting to fulfill the obligations associated with *dharma* (i.e. perpetuating an unbroken lineage devoted to the scriptures of Hinduism) was associated with increased stigma, especially via reducing marriage prospects for the individual and kin. Among immigrant populations, in a sample of Latina Caribbean mothers, qualitative findings revealed that continued medication use indicated enduring disability among their behaviourally-disordered children, thus leading to higher stigma.<sup>67</sup>

## Discussion

Several main trends emerged from the categories we reviewed. That far fewer studies of affiliate and structural stigma were conducted reveals a glaring gap in the literature, as affiliate stigma appears to be a major stigma concern for many of the evaluated groups and structural stigma may be particularly problematic for immigrant minority groups. Examining region of study further indicated that our understanding of culture-specific stigma dynamics within huge sectors of the world—in particular, Eurasia, Africa and South America—remains underdeveloped. In terms of specific ethnic group studied, African American and Latino groups were most studied within the USA, and Asian/Pacific Islander groups were represented most among international settings. Regarding type of mental illness, depression and schizophrenia were most widely studied, which befits the emphasis on these disorders as sources of disability globally.<sup>68</sup>

In-depth reviews of stigma measures quantitatively derived from non-Western European groups indicated a paucity of emically-derived measures, thus revealing a new area for measurement innovation. Interestingly, three of the four emically-derived measures appeared to correspond most closely to aspects of 'what matters most' in everyday lived interaction among distinct Asian groups, as constructs of impacts upon family,<sup>26</sup> 'face loss'<sup>27</sup> and loss of family status<sup>28</sup> were assessed. Whereas each one of these constructs identifies an important cultural value among many Asian groups, linking them together via threat to perpetuating the lineage, as indicated by our analysis of 'what matters most' among these groups,<sup>36</sup> enables a direct formulation of how these culture-specific constructs impact stigma. Extending results from our narrative analysis of qualitative and mixed-method stigma studies, the 'what matters most' framework appears to have particular utility in terms of identifying culturally-specific stigma dynamics and in articulating how these cultural dynamics impact stigma. For Latino American groups, it appears that mental illness (and taking psychiatric medications) may threaten fundamental lived engagements of being resilient and hard-working, fighting against adversity and taking advantage of opportunities following immigration.



Likewise, for African American groups, it appears that greater everyday involvement with religious institutions and family life in the context of historic discrimination is linked with greater self-reliance, thus precipitating greater stigma when mental illness is revealed. Accordingly, these formulations of stigma via a 'what matters most' perspective might be targeted and operationalized via new culture-specific, quantitative instruments designed to assess how stigma threatens the activities that define 'personhood' in these groups.

Developing culture-specific measures of stigma from the perspective of 'what matters most' for participants offers a conceptual advantage over generic qualitative approaches that are primarily inductive and/or focus on identifying general 'cultural values'.<sup>10</sup> Our review indicates that the vast majority of qualitative studies (27/33; 81.8%) used such an approach. Instead of identifying a general set of cultural values that might be associated with a cultural group, the 'what matters most' approach enables researchers to formulate, then capture the aspects of stigma that block an individual from meaningfully participating in the fundamental behavioural routines (i.e. the everyday things that they 'do') that are essential for 'personhood' for cultural group members (i.e. 'moral experience'). Measures of stigma based on 'what matters most' also may augment standard stigma measures by offering additional utility in predicting outcomes of interest (e.g. self-esteem, depression<sup>69</sup>). We propose that the predictive validity from a 'culture-specific' stigma measure would significantly predict an outcome of interest (e.g. depression) over and above the standard stigma scale. Prior work supports this possibility. For example, Yang<sup>36</sup> operationalized the 'fundamental lived engagement' of threat to family lineage among Chinese groups via the perceived presence of psychiatric illness in a potential marriage partner's ancestry. Evaluation in a nationally-representative sample of Chinese and European Americans demonstrated that this Chinese-specific threat to stigma demonstrated additive utility in predicting social distance towards psychiatric illness even after accounting for 'universal' threat mechanisms (i.e. perceptions of controllability and dangerousness).

Although local adaptation of stigma measures offers important benefits, it also raises complicated issues in the comparison of stigma across settings. Comparing stigma across cultural groups with scales consisting of different items is more complex than typical epidemiological comparisons using standardized instruments.<sup>66</sup> This issue might be mitigated by administering both standardized and culture-specific measures of stigma, thus enabling direct comparison as well as assessment of local forms of stigma. Comparison of culture-specific forms of stigma, although not easily conducted quantitatively, might be

evaluated for commonalities and variations across cultures, thus promoting further understanding of stigma's 'universal' effects. Lastly, use of culturally-valid stigma instruments might promote anti-stigma interventions that are effective within local contexts and enable effective evaluation of their impact.

Study limitations include the exclusion of foreign-language articles, which biased against including studies from non-English speaking, international contexts. This might have lowered our estimate of the proportion of studies conducted within primarily non-English speaking contexts (e.g. Asia, South America), as well as led to an underestimate of studies that quantitatively developed measures incorporating culture-specific concepts. Another potential limitation of our search strategy is that we did not specifically include terms of culture-specific idioms of distress, and thus may have missed studies addressing the cultural expression of stigma towards mental illness. Similarly, by using broad search terms such as 'culture' for our Google Scholar search, we may have missed studies on specific regions or ethnicities (e.g. 'Puerto Rican'); further, derivatives of search terms (e.g. 'stereotyping', 'stereotypes' for the term 'stereotype') were not included in our search. Most studies in our review used small convenience samples, so that findings were specific to certain subgroups and may not apply to all group members. The choice of stigma measure also varied from study to study, thus potentially undermining identification of cogent, culturally-specific stigma constructs.

We also propose the following recommendations for future research. First, one of the most striking findings is that the vast majority of qualitative studies on stigma were conducted with generic inductive qualitative methods without the use of clear, stigma-specific frameworks. We intend this analysis, in operationalizing culture via 'moral experience' or 'what is most at stake', to address this key issue and to guide future research. Second, initial qualitative work has begun<sup>36</sup> but differentiating between measurement of structural factors and potentially closely-intertwined cultural factors deserves close theoretical and empirical attention. Third, as measures of culture-specific stigma develop, whether a measure captures a meaningful component of 'what matters most' in a cultural group should be empirically tested. For example, the ability of what is identified as 'what matters most' might be assessed as to its utility to predict stigma-related outcomes (e.g. depression) in one group (e.g. residents in mainland China) compared with another closely-associated cultural group (less acculturated Chinese immigrants to the USA<sup>70</sup>). Fourth, epistemological assumptions of the constructs that underlie standardized measures of stigma may shift as our knowledge of what domains of stigma are common and

unique to various cultural groups increases. Further, Western European groups despite their heterogeneity also exhibit cultural dynamics impacting stigma that might be identified and operationalized by future studies. The extant stigma measures developed for Western European groups appeared to adopt a 'universalist' perspective and did not explicitly incorporate anthropological perspectives; thus the 'what matters most' approach might also augment the study of stigma in these groups. Finally, the 'what matters most' framework does not incorporate other vulnerabilities endured by the mentally ill, such as physical and human rights abuses, which comprise important aspects of their stigma experience. We intend this systematic review to provide a foundation by which to design future theoretically-driven studies to identify and measure culture-specific aspects of stigma. We hope that future research will address these domains to advance this nascent and vitally important area.

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## Supplementary Data

Supplementary data are available at *IJE* online.

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## References

- Collins PY, Patel V, Joestl SS *et al.* Grand challenges in global mental health. *Nature* 2011;475:27–30.
- Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M; INDIGO Study Group. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet* 2009;373:408–15.
- Esses VM, Zanna MP. Mood and the expression of ethnic stereotypes. *J Pers Soc Psychol* 1995;69:1052–68.
- Lin MH, Kwan VS, Cheung A, Fiske ST. Stereotype content model explains prejudice for an envied outgroup: Scale of anti-Asian American stereotypes. *Pers Soc Psychol Bull* 2005;31:34–47.
- Crandall CS, Martinez R. Culture, ideology, and anti-fat attitudes. *Pers Soc Psychol Bull* 1996;22:1165–76.
- Stangor C, Crandall CS. Threat and the social construction of stigma. In: Hetherington TF, Kleck RE, Hebl MR, Hall JG (eds). *The Social Psychology of Stigma*. New York: Guilford Press, 2000.
- Stuber J, Galea S, Link BG. Smoking and the emergence of a stigmatized social status. *Soc Sci Med* 2008;67:420–30.
- Link BG, Yang LH, Phelan JC, Collins PY. Measuring mental illness stigma. *Schizophr Bull* 2004;30:511–41.
- Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Serv Res* 2010;10:80.
- Abdullah T, Brown TL. Mental illness stigma and ethnocultural beliefs, values, and norms: an integrative review. *Clin Psychol Rev* 2011;31:934–48.
- Mak WW, Poon CY, Pun LY, Cheung SF. Meta-analysis of stigma and mental health. *Soc Sci Med* 2007;65:245–61.
- Mora-Rios J, Bautista-Aguilar N, Natera G, Pedersen D. Cultural adaptation of instruments to measure stigma and mental illness in Mexico City. *Salud Mental* 2013;36:18.
- Flaherty JA, Gaviria FM, Pathak D *et al.* Developing instruments for cross-cultural psychiatric research. *J Nerv Ment Dis* 1988;176:257–63.
- Ambert AM, Adler PA, Adler P, Detzner DF. Understanding and evaluating qualitative research. *J Marriage Fam* 1995;57:879–93.
- Mays N, Pope C. Rigour and qualitative research. *BMJ* 1995;311:109.
- Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8:45.
- Yang LH, Kleinman A, Link BG, Phelan JC, Lee S, Good B. Culture and stigma: adding moral experience to stigma theory. *Soc Sci Med* 2007;64:1524–35.
- Kleinman A. *What Really Matters: Living a Moral Life Amidst Uncertainty and Danger*. Oxford, UK: Oxford University Press, 2006.
- Yang LH, Kleinman A. 'Face' and the embodiment of stigma: schizophrenia and AIDS in China. *Soc Sci Med* 2008;67:398–408.
- Yang LH, Purdie-Vaughns V, Kotabe H *et al.* Culture, threat, and mental illness stigma: identifying culture-specific threat among Chinese American groups. *Soc Sci Med* 2013;88:56–67.
- Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 2009;151:264–69.
- Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, 1963.
- Jones EE, Farina A, Hastorf AH *et al.* *Social Stigma: The Psychology of Marked Relationships*. New York: WH Freeman, 1984.
- Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol* 2001;27:363–85.
- Thornicroft G. *Shunned: Discrimination Against People With Mental Illness*. Oxford, UK: Oxford University Press, 2006.
- Tsang HW, Tam PK, Chan F, Cheung WM. Stigmatizing attitudes towards individuals with mental illness in Hong Kong: implications for their recovery. *J Community Psychol* 2003;31:383–96.

27. Mak WW, Cheung, RY. Affiliate stigma among caregivers of people with intellectual disability or mental illness. *J Appl Res Intellect Disabil* 2008;21:532–45.
28. Gilbert P, Bhundia R, Mitra R, McEwan K, Irons C, Sanghera J. Cultural differences in shame-focused attitudes towards mental health problems in Asian and non-Asian student women. *Ment Health Relig Cult* 2007;10:127–41.
29. Interian A, Ang A, Gara MA, Link BG, Rodriguez MA, Vega WA. Stigma and depression treatment utilization among Latinos: utility of four stigma measures. *Psychiatr Serv* 2010;61:373.
30. Mwakikagile G. *Relations Between Africans and African Americans: Misconceptions, Myths and Realities*. Minneapolis, MN: Intercontinental Books, 2007.
31. Franz L, Carter T, Leiner AS, Bergner E, Thompson NJ, Compton MT. Stigma and treatment delay in first-episode psychosis: a grounded theory study. *Early Interv Psychiatry* 2010;4:47–56.
32. Knifton L. Understanding and addressing the stigma of mental illness with ethnic minority communities. *Health Sociol Rev* 2012;21:287–98.
33. Read UM, Adii bokah E, Nyame S. Local suffering and the global discourse of mental health and human rights: an ethnographic study of responses to mental illness in rural Ghana. *Global Health* 2009;5:13.
34. Kranke D, Guada J, Kranke B, Floersch J. What do African American youth with a mental illness think about help-seeking and psychiatric medication?: origins of stigmatizing attitudes. *Soc Work Ment Health* 2010;10:53–71.
35. Collins PY, Von Unger H, Armbrister A. Church ladies, good girls, and locas: stigma and the intersection of gender, ethnicity, mental illness, and sexuality in relation to HIV risk. *Soc Sci Med* 2008;67:389–97.
36. Yang LH, Chen F, Sia KJ, Lam JJ, Lam K, Ngo H, Lee S, Kleinman A, Good B. What matters most: a cultural mechanism moderating structural vulnerability and moral experience of mental illness stigma. *Soc Sci Med* 103:84–93.
37. Held RF, DePue J, Rosen R *et al*. Patient and health care provider views of depressive symptoms and diabetes in American Samoa. *Cultur Divers Ethnic Minor Psychol* 2010;16:461–7.
38. Wang JY. Service users' personal experience and interpretation of mental illness: Oriental narratives. *Int J Soc Psychiatry* 2011;58:425–32.
39. Wong DFK. Uncovering sociocultural factors influencing the pathway to care of Chinese caregivers with relatives suffering from early psychosis in Hong Kong. *Cult Med Psychiatry* 2007;31:51–71.
40. Pun SH, Ma JL, Lai KC. In search of perfect motherhood for imperfect childhood—experiences of 22 Chinese mothers. *Child Fami Soc Work J* 2004;9:285–93.
41. Sadavoy J, Meier R, Ong AYM. Barriers to access to mental health services for ethnic seniors: the Toronto study. *Can J Psychiatry* 2004;49:192–99.
42. Thompson S, Manderson L, Woelz-Stirling N, Cahill A, Kelaher M. The social and cultural context of the mental health of Filipinas in Queensland. *Aust N Z J Psychiatry* 2002;36:681–87.
43. Fancher TL, Ton H, Le Meyer O, Ho T, Paterniti DA. Discussing depression with Vietnamese American patients. *J Immigr Minor Health* 2010;12:263–66.
44. Koo K. Carers' representations of affective mental disorders in British Chinese communities. *Sociol Health Illn* 2012;34:1140–55.
45. Lin SY. Beliefs about causes, symptoms, and stigma associated with severe mental illness among 'highly acculturated' Chinese-American patients. *Int J Soc Psychiatry* 2012;59:636–45.
46. Conrad MM, Pacquiao DF. Manifestation, attribution, and coping with depression among Asian Indians from the perspectives of health care practitioners. *J Transcult Nurs* 2005;16:32–40.
47. Guarnaccia PJ, Parka P, Deschamps A, Milstein G, Argiles N. Si dios quiere: Hispanic families' experiences of caring for a seriously mentally ill family member. *Cult Med Psychiatry* 1992;16:187–215.
48. Pincay IEM, Guarnaccia PJ. 'It's like going through an earthquake': anthropological perspectives on depression among Latino immigrants. *J Immigr Minor Health* 2007;9:17–28.
49. Cabassa LJ, Contreras S, Aragón R, Molina GB, Baron M. Focus group evaluation of 'secret feelings': a depression fotonovela for Latinos with limited English proficiency. *Health Promot Pract* 2011;12:840–47.
50. Cabassa LJ, Hansen MC, Palinkas LA, Ell K. Azúcar y nervios: explanatory models and treatment experiences of Hispanics with diabetes and depression. *Soc Sci Med* 2008;66:2413–24.
51. Willging C, Salvador M, Kano M. Pragmatic help seeking: how sexual and gender minority groups access mental health care in a rural state. *Psychiatr Serv* 2006;57:871–74.
52. Interian A, Martinez IE, Guarnaccia PJ, Vega WA, Escobar JL. A qualitative analysis of the perception of stigma among Latinos receiving antidepressants. *Psychiatr Serv* 2007;58:1591–4.
53. Hines-Martin V, Malone M, Kim S, Brown-Piper A. Barriers to mental health care access in an African American population. *Issues Ment Health Nurs* 2003;24:237–56.
54. Joo JH, Wittink M, Dahlberg B. Shared conceptualizations and divergent experiences of counseling among African American and white older adults. *Qual Health Res* 2011;21:1065–74.
55. Alverson H, Drake R, Carpenter-Song E, Chu E, Ritsema M, Smith, B. Ethno-cultural variations in mental illness discourse: some implications for building therapeutic alliances. *Psychiatr Serv* 2007;58:1541–46.
56. Carpenter-Song E, Chu E, Drake RE, Ritsema M, Smith B, Alverson H. Ethno-cultural variations in the experience and meaning of mental illness and treatment: implications for access and utilization. *Transcult Psychiatry* 2010;47:224–51.
57. Johnson M, Mills TL, DeLeon JM, Hartzema AG, Haddad J. Lives in isolation: stories and struggles of low-income African American Women with panic disorder. *CNS Neurosci Ther* 2009;15:210–19.
58. Whittaker S, Hardy G, Lewis K, Buchan L. An exploration of psychological well-being with young Somali refugee and asylum-seeker women. *Clin Child Psychol Psychiatry* 2005;10:177–96.
59. Kapungwe A, Cooper S, Mwanza J *et al*. Mental illness-stigma and discrimination in Zambia. *Afr J Psychiatry* 2010;13:192–203.
60. Schulze B, Angermeyer MC. Subjective experiences of stigma: a focus group study of schizophrenic patients, their relatives, and mental health professionals. *Soc Sci Med* 2003;56:299–312.
61. Murry VM, Heflinger CA, Suiter SV, Brody GH. Examining perceptions about mental health care and help-seeking among rural

- African American families of adolescents. *J Youth Adolesc* 2011;**40**:1118–31.
62. Corrigan PW, Kuwabara S, Tsang H *et al.* Disability and work-related attitudes in employers from Beijing, Chicago, and Hong Kong. *Int J Rehabil Res* 2008;**31**:347–50.
63. Corrigan PW, Tsang HW, Shi K, Lam CS, Larson J. Chinese and American employers' perspectives regarding hiring people with behaviorally driven health conditions: the role of stigma. *Soc Sci Med* 2010;**71**:2162–69.
64. Lindsey MA, Joe S, Nebbitt V. Family matters: the role of mental health stigma and social support on depressive symptoms and subsequent help seeking among African American boys. *J Black Psychol* 2010;**36**:458–82.
65. Johnson LR, Mayanja MK, Bangirana P, Kizito S. Contrasting concepts of depression in Uganda: implications for service delivery in a multicultural context. *Am J Orthopsychiatry* 2009;**79**:275–89.
66. Weiss MG, Jadhav S, Raguram R, Vounatsou P, Littlewood R. Psychiatric stigma across cultures: local validation in Bangalore and London. *Anthropol Med* 2001;**8**:71–87.
67. Arcia E, Castillo H, Fernández MC. Maternal cognitions about distress and anxiety in young Latino children with disruptive behaviors. *Transcult Psychiatry* 2004;**41**:99–119.
68. Prince M, Patel V, Saxena S *et al.* No health without mental health. *Lancet* 2007;**370**:859–77.
69. Yang LH, Valencia E, Alvarado R *et al.* A theoretical and empirical framework for constructing culture-specific stigma instruments for Chile. *Cad Saude Colet* 2013;**21**:71–79.
70. Yang LH, Corsini-Munt S, Link B, Phelan J. Beliefs in traditional Chinese medicine efficacy among Chinese Americans: implications for mental health service utilization. *J Nerv Ment Dis* 2009;**197**:207–10.