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Perspectives of family members participating in cultural assessment of psychiatric disorders: Findings from the DSM-5 International Field Trial

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Abstract

Despite the important roles families play in the lives of many persons with mental illness across cultures, there is a dearth of data worldwide on how family members perceive the process of cultural assessment as well as to how to best include them. This study addresses this gap in our knowledge through analysis of data collected across six countries as part of a DSM-5 Field Trial of the Cultural Formulation Interview (CFI). At clinician discretion, individuals who accompanied patients to the clinic visit (i.e. patient companions) at the time the CFI was conducted were invited to participate in the cultural assessment and answer questions about their experience. The specific aims of this paper are (1) to describe patterns of participation of patient companions in the CFI across the six countries, and (2) to examine the comparative feasibility, acceptability, and clinical utility of the CFI from companion perspectives through analysis of both quantitative and qualitative data. Among the 321 patient interviews, only 86 (at 4 of 12 sites) included companions, all of whom were family members or other relatives. The utility, feasibility and acceptability of the CFI were rated favorably by relatives, supported by qualitative analyses of debriefing interviews. Cross-site differences in frequency of accompaniment merit further study.

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Introduction

The DSM-5 Cultural Formulation Interview (CFI) is a tool to assist clinicians in assessing cultural issues in diagnosis and treatment (Lewis-Fernandez et al., 2014; Lewis-Fernandez et al., in press). The inclusion of family members and others who accompany patients to clinic visits (patient companions) may help clinicians differentiate normal from abnormal behaviors for patients from diverse cultural backgrounds that may be unfamiliar to the clinician (Aggarwal & Rohrbaugh, 2011). This can be particularly important when patients cannot provide a coherent or accurate account due to cognitive impairment or severe psychosis (Estroff, 2003). Even for cognitively intact patients, including family members may align with patient preferences and/or cultural norms and give clinicians the opportunity to supplement the patient’s history and evaluate the social support system (Aggarwal et al., in press; Diaz et al., in press; Hinton et al., 2014). There is, however, a dearth of data worldwide on how family members perceive the process of cultural assessment and how to best include them. Understanding cross-cultural similarities and differences in how cultural assessment is experienced by relatives can help to inform clinical practice with diverse populations.

This study addresses this gap in our knowledge through an analysis of data collected across six countries as part of a DSM-5 Field Trial. The purpose of the field trial was to field-test a preliminary version of the core CFI and modify the tool to enhance its feasibility, acceptability, and clinical utility cross-culturally. The core *CFI* refers to the 16-item interview that yields a basic cultural assessment during a clinical evaluation and can be used with any patient in any clinical setting by any clinician. This core assessment can be supplemented with an informant version of the CFI and 12 supplementary models that expand the number of questions by cultural domain or include topics of additional interest for certain populations (Lewis-Fernandez et al., in press). The latter two components of the CFI were not included in the international field trial and are not discussed in this article.

The goal of this paper is to report how family members experience the process of cultural assessment. The specific aims of this paper are: 1) to describe patterns of participation of patient companions across the 6 countries, and 2) to examine the comparative feasibility, acceptability and clinical utility of the CFI from companion perspectives.

Methods

Study setting and design

The field trial was designed by experts in cultural psychiatry through the DSM-5 Cross-Cultural Issues Subgroup (DCCIS) (Aggarwal et al., 2013; Lewis-Fernández et al., 2014). The New York State Psychiatric Institute (NYSPI) and Columbia University Department of Psychiatry formed a single research site and coordinated logistics for all sites. The study started in November 2011 and ended in September 2012. Each site aimed to enroll at least 30 patients and partnered with local clinics to meet targeted enrolment across the USA (five sites), Peru (one site), Canada (two sites), the Netherlands (one site), Kenya (one site), and India (two sites).

New and extant patients were enrolled. For new patients, treating clinicians were the research clinicians. Extant patients were approached by treating clinicians to be interviewed by research clinicians using the core CFI. Clinicians could, at their discretion, also invite companions (i.e., relatives or others who accompanied the patient) to participate in the interview. In all cases, research clinicians were new to patients. Informed consent was obtained for all patients during referral. The interview with the research clinician consisted of the core CFI, followed by a routine diagnostic assessment. Companions who participated also provided informed consent prior to the interview. All sessions were audio-taped unless the patients did not provide consent. Patients, their companions, and research clinicians completed questionnaires before and after the interview. The study was approved by each site's Institutional Review/Ethics Board (IRB)

Participants

Eligible patients were of any racial or ethnic background; age 18 years or older; fluent in the languages of clinicians, and could have any psychiatric diagnosis. Patients and clinicians were matched by language to avoid use of translators or cultural brokers who could introduce cultural information not obtained through the CFI. Patients were excluded if they were acutely suicidal or homicidal; intoxicated or in substance withdrawal; or had any condition that could interfere with the interview such as dementia, mental retardation, or florid psychosis. Patients were purposively sampled and read a standard recruitment script across all sites. Site primary investigators decided whether to enroll companions of patients in the study based on local IRB requirements and practice guidelines.

Eligible research clinicians conducting the CFI were required to have a terminal degree (MD, MSW, PhD, APRN) permitting them to see patients, consistent with professional requirements in each country. After being introduced to the field trial aims and providing informed consent, clinicians attended a standard 2-h CFI training session consisting of reviewing the core CFI's written guidelines, a video demonstration, and interactive behavioral simulations among clinicians. Clinicians were excluded only if they could not attend the training and were excluded from interviewing extant patients since prior knowledge could confound field trial's aims.

Assessments

Before the interview, patients and research clinicians completed routine demographic surveys. When companions were present, their relationship to the patient was recorded. All patients completed a consent process. The CFI session included the core CFI followed by a routine diagnostic assessment. A copy of the core CFI and its written guidelines were provided to each clinician before each interview.

After the interview, patients and clinicians were interviewed about the feasibility, acceptability, and clinical utility of the core CFI (reported elsewhere) using a debriefing questionnaire and a semi-structured interview. Researchers at each site also completed a census form that listed the number of people accompanying the patient and their relationships to the patient during (1) the CFI session, and (2) the debriefing period after the CFI session. Companions were also invited to complete a closed-ended debriefing questionnaire and an open-ended, semi-structured interview on CFI feasibility, acceptability, and clinical utility if they attended the CFI session. If multiple companions were present, the patient was asked to identify one person to complete the debriefing questionnaire and semi-structured interview. As with other DSM-5 field trials (Clarke et al., 2014), instruments to test these outcomes were created specifically for the CFI field trial. The debriefing instrument for patients' relatives and other companions consisted of self-report Likert-scale items assessing feasibility (three items), acceptability (three items), and perceived clinical utility (eight items), coded as 'strongly disagree', 'disagree', 'agree', and 'strongly agree'. Items were selected for measurement by the DCCIS based on constructs from implementation science (Proctor et al., 2013). To improve internal consistency, two items were dropped from the feasibility and acceptability indices, leaving each with two remaining items (see below). The full questionnaire is included in Table 1, including the two questions that were dropped. Open-ended questions were developed to elicit the perspectives on the CFI, including positive and negative perceptions (see Table 2).

DCCIS reviewed all instruments. During the debriefing process, research staff was instructed to record key elements of responses from patients, companions, and clinicians to the open-ended questions, generating a written record of responses. Research staff uploaded all forms into a database managed centrally by the Center of Excellence for Cultural Competence at NYSPI.

Analysis

As described elsewhere (Paralikar, et al., 2015), for the purposes of analysis, negative responses were coded as either −2 (strongly disagree) or −1 (disagree) and positive responses as either 1 (agree) or 2 (strongly agree). This created the possibility of a neutral value (i.e., '0') for the mean summary value. Missing responses were imputed using the site-specific mean for the corresponding question. Cronbach's α was used to assess the internal consistency of each of three indices. For both the acceptability and feasibility indices, dropping one item each that was negatively-worded (no. 10 from the acceptability subscale and no. 12 for the feasibility subscale) resulted in a significant improvement in the internal consistency (from 0.28 to 0.63 for the *feasibility* subscale and from 0.33 to 0.44 for the *acceptability* subscale). Both items were subsequently excluded from the composite index which included the 12 remaining items in three indices with a Cronbach's alpha of 0.82. This approach is also supported by prior research on cross-cultural variation in responses to negatively worded survey items (Wu, 2008). Patient and family characteristics were compared across sites using Kruskal-Wallis test for continuous variables not normally distributed, and Fisher's exact test for categorical variables. The responses for individual items were treated as ordinal and differences across sites and were evaluated using generalized estimating equations (GEE) models that adjusted for clustering by clinician (i.e. because at every site clinicians carried out the cultural assessment of several patients). Similarly, GEE for continuous data, accounting for the nesting of patients within clinicians, were used to compare the subscales and the composite scale across sites. SAS (SAS/STAT version 9.4, Cary, NC) was used for all statistical analyses.

The responses to the nine open-ended questions in the debriefing interview were coded thematically in a stepwise process using standard approaches for descriptive thematic analysis (Chenail, 2011; Sandelowski, 2000). First, two coders independently reviewed the qualitative data and developed a list of thematic categories. Next, the results of this initial coding were compared, differences were discussed and resolved through a consensus process, and a final list of thematic categories was generated. Representative quotes were identified for each category.

Results

Rate of accompaniment across sites

Of the 321 patients who participated in the field trial, 86 cultural assessments included at least one patient companion. These 86 accompanied assessments occurred in 25% (4/12) of the individual sites and 50% (3/6) of the countries represented. Among sites that included someone other than the patient in the cultural assessment, there was substantial variation, ranging from 100% in Kenya to 20% in the Netherlands. Because of possible clinic-related factors, we also included the proportion of patients who are new to the clinic in Table 3. There was no clear association between the site's proportion of new patients and the proportion of accompanied visits. For example, while US sites had the smallest proportion of new patients and no participation of close associates in the CFI, approximately 1/3 of the patients at the Canada sites and Peru site were new to the sites and yet neither site reported accompanied visits.

Patient and companion characteristics across sites

While 86 visits across 4 sites were accompanied, debriefing data were only available for 71 interviews at the 3 sites shown in Table 4 (no debriefing was available at the Netherlands site and was missing for 9 accompanied visits at the New Delhi site). Among these three sites, there were significant differences in the patient's marital status and primary psychiatric diagnosis. Despite cross-site similarities in mean age of patients, in Nairobi only 30% of patients were married compared with 45% in New Delhi and 69% in Pune. In terms of diagnosis, psychosis and substance dependence/abuse disorders were most frequent at the Nairobi site. All companions were relatives, such as a spouse, sibling, adult child or other relative. Companions were most often siblings in Nairobi and parents in the India sites. There was no significant difference in the proportion of male and female relatives.

Cross-site comparison of feasibility, acceptability, and clinical utility

While feasibility, acceptability, and clinical utility were generally positive across the three usable sites (with means higher than 1 (agree) on a scale from −2 to 2 for all indices across all sites), there were significant site differences for utility and acceptability, with higher mean scores for these indices in Nairobi. As shown in Table 5, there was also significant cross-site difference in the composite mean score, with Nairobi again having the highest score.

Cross-site comparison of individual items

Means for the individual items are shown in Table 1, including the two negatively worded items (no.10 and no.12) that were not included in the feasibility, acceptability, and clinical utility indices as described above under Methods. Cross-site means for all of the items except for 10 and 12 were above 1, indicating a positive view of the CFI in many respects. At the two Indian sites, however, approximately one-third to one-half of relatives felt the CFI was ‘too persona’ l or took ‘too much time’. There were also significant cross-site differences in the scores for individual items, with the Nairobi site participants tending to view the CFI in more positive terms compared with participants at the Indian sites.

Themes identified through qualitative analysis

The responses to the open-ended questions were often quite brief, ranging from a few words to four or five sentences. Companion responses fell into two broad topics: (1) Positive perceptions of the CFI interview process and (2) areas for improvement. On the positive side, relatives appreciated how the CFI helped the patient express themselves, talk about their background, and discuss their problem in an in-depth way. Participation in the CFI interview also gave relatives the opportunity to understand the patient’s problem and to express their own opinions. Several relatives felt the CFI questions were difficult to understand, particularly for those with lower literacy, a suggested improvement to the CFI that was not highlighted in the quantitative findings. In addition, some relatives identified specific issues they wished had been explored in more detail during the interview. Table 6 summarizes the major themes with representative quotes. The list of open-ended debriefing questions is provided in Table 2.

Discussion

To our knowledge, this is the first comparative, cross-national study to examine how relatives participate in and experience a psychiatric cultural assessment. This study has several important preliminary findings. First, we found that, among those companions who participated in the version of the CFI used in the field trials, their perceptions of its acceptability and clinical utility were generally favorable (i.e. mean scores of greater than 1 on a scale from −2 to 2 with 2 being most favorable). While the mean for the feasibility index was similarly favorable, these results need to be interpreted with caution because of the relatively low internal consistency of this two-item index. However there were also significant cross-site differences in the mean scores for each index and the composite index, with the Nairobi site having the most positive scores for each index compared with the two India sites. This suggests that there are also important cross-cultural differences in how relatives perceived the CFI.

The qualitative data supports this interpretation of the quantitative data, identifying positive aspects of the CFI. Relatives valued the in-depth exploration of the patient’s problem and the opportunity to share their own views and to participate in the assessment process. While the CFI was generally well-received, areas for improvement were also identified. Some relatives found the CFI too time-consuming and the questions too personal or difficult to understand. Notably, these barriers are similar to those reported by patients in qualitative analyses from the New York City site, leading to revision of the CFI for inclusion in DSM-5 (Aggarwal et al., 2013; Lewis-Fernández et al., in press).

A second, unexpected finding that limits the conclusions we can draw from this preliminary study was the cross-site difference in companion participation. Several explanations may be possible. For example, the involvement of close associates in mental health services may be stronger in certain cultural settings, such as Nairobi, compared with others. In other settings with a more individualistic orientation to mental healthcare emphasizing patient privacy and confidentiality, as in the USA and Canada, family involvement may be limited. Provider-level explanations are also possible, including clinician barriers to involving family members, such as lack of time or motivation. Organizational-level explanations may also play a role: in India and Kenya where new patients were enrolled, administrators may have included family members to optimize treatment. In contrast, family members may have been excluded in other countries if administrators or other decision-makers did not provide guidelines to clinicians for companion involvement. The nearly equal representation of men and women among the companions was unexpected and deserves further examination in larger and more representative samples of patients with mental illness.

This study has several limitations. First, this study is based on data from three countries and the overall sample size is modest, making this a preliminary report, but useful nonetheless. Second, patients, their companions, and clinicians were all purposively sampled and may not be fully representative. For example, family members or other companions likely to view their relative's participation in the field trials negatively might have been less likely to participate in the CFI, resulting in a selection bias towards companions who were more favorably predisposed. Third, the study interview consisted of the CFI session followed by the routine diagnostic assessment. All clinicians were asked to inform patients when they would transition from the CFI to the routine assessment. It is possible that some respondents, especially those new to mental health services, may not have differentiated CFI from routine questions during debriefing interviews. Fourth, sites varied in the extent to which they transcribed responses, some opting for full transcriptions and others opting for brief summaries. The qualitative findings reported here were meant to amplify the quantitative findings and to serve as preliminary findings to inform further studies rather than a saturated account of thematic categories. Finally and as noted previously, because the feasibility scale had a relatively low internal consistency the results for this index should be interpreted cautiously.

Despite these limitations, this study provides support for the involvement of relatives and others who may accompany patients within cultural assessments. The cultural views of patient companions can be a crucial element of the treatment process, especially among patients with severe impairments due to mental illness, impacting the accuracy of diagnostic assessment, patient-clinician rapport, family and patient engagement, treatment adherence and retention, and eventual outcome (Aggarwal et al., in press; Hinton et al., in press; Lefley, 1996). Identifying the role of the family in care is important for developing a culturally informed treatment plan. For example, relatives and other companions can be included as supports during crises, potentially avoiding a costly hospitalization (Diaz et al., in press). Improvements in the DSM-5 core CFI as a result of the field trial, as well as the subsequent development of an informant version, build on the initial feasibility, acceptability, and perceived clinical utility of the core CFI for use among family members and other companions who are available during clinic visits.

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Table 1

Cross-site comparison of means for individual items (range is from −2 = strongly disagree to 2 = strongly agree)

Item	Pune (n = 12)	New Delhi (n = 29)	Nairobi (n = 30)	All sites (n = 71)	*P*-value*
Utility					
1. Helped me explain the patient's main concerns	1.33 (0.89)	1.31 (0.47)	1.37 (0.67)	1.34 (0.63)	0.48
2. Helped communicate important aspects of patient's background, such as religious faith and/or culture	1.00 (1.04)	0.86 (0.83)	1.37 (0.49)	1.10 (0.78)	0.06
3. Helped me understand how the patient's background and current situation affect the patient's problem	0.67 (1.07)	1.07 (0.70)	1.60 (0.50)	1.23 (0.78)	0.04
4. Helped me explain what kinds of help the patient would like	1.17 (1.11)	1.21 (0.41)	1.43 (0.82)	1.30 (0.74)	0.04
5. Gave me confidence that the clinician understood the patient's situation	1.17 (0.83)	1.21 (0.41)	1.33 (0.66)	1.25 (0.60)	0.39
6. Helped me identify things that would get in the way of the patient's treatment	0.75 (1.14)	0.72 (0.84)	1.47 (0.51)	1.04 (0.85)	0.03
7. Encouraged me to share information that I might not have mentioned otherwise	1.25 (1.14)	0.93 (0.88)	1.20 (0.61)	1.10 (0.83)	0.28
8. Were useful overall	1.58 (0.51)	1.41 (0.50)	1.73 (0.45)	1.58 (0.50)	0.22
Feasibility					
9. Were easy to understand	1.00 (1.04)	1.28 (0.45)	1.27 (0.45)	1.23 (0.59)	0.91
10. Took more time to share the patient's perspective than I wanted	0.17 (1.27)	0.93 (0.88)	−1.00 (0.00)	−0.01 (1.16)	0.004
11. Improved the flow of the interview	1.58 (0.51)	1.28 (0.45)	1.73 (0.45)	1.52 (0.50)	0.02
Acceptability					
12. Were too personal	0.08 (1.16)	−0.21 (1.05)	−1.00 (0.00)	−0.49 (0.92)	0.02
13. Should be asked by every clinician	1.08 (0.79)	1.31 (0.47)	1.33 (0.48)	1.28 (0.54)	0.64
14. Help me feel more at ease during the interview	1.25 (0.87)	1.24 (0.44)	1.90 (0.31)	1.52 (0.58)	0.006

[*] Sites were compared using generalized estimating equation models for ordinal data adjusting for clustering by clinician

Table 2

Open-ended debriefing questions

1. Overall, how did you feel answering these questions about your perspectives on your relative's problems?

2. How did the questions affect what you talked about with the clinician regarding your relative?

3. How did the CFI affect the relationship with the clinician?

4. How different were these questions from those of other clinicians who see your relative?

5. How did the CFI affect what you think or feel about mental health services?

6. What was most helpful about the questions of the CFI? Least helpful?

7. Are there any particular CFI questions that you think should be changed, removed, perhaps because they were unclear?

8. Are there any additional questions that were not asked during the CFI, but should be included?

9. How do you think the CFI might affect the care of your relative?

Table 3

Relative participation in CFI field trials across 6 countries (12 sites)*

Countries and sites	Number of patients	Number (%) of patients with accompaniment	Number of patients new to CFI clinic
Canada (Montreal, Toronto)	33	0	33 (100%)
India			
New Delhi	67	38 (57%)	67 (100%)
Pune	36	12 (33%)	36 (100%)
Kenya (Nairobi)	30	30 (100%)	0
Netherlands (Beilen, Oegstgeest, The Hague)	30	6 (20%)	20 (66.67%)
Peru (Lima)	34	0	34 (100%)
US (New York, New Haven, Sacramento, San Francisco, Minneapolis)	91	0	1 (0.31%)
Total	321	86 (27%)	191 (59.5%)

*A11 cities listed were individual sites except for the three cities in the Netherlands which were considered as one site

Table 4

Comparison of patient and relative characteristics across 3 sites

	Pune (n = 12)	New Delhi (n = 29)	Nairobi (n = 30)	*P*-value[*]
Patient characteristics				
Mean age (sd)	34 (14)	32 (11)	31 (11)	0.92
Women, n (%)	6 (50%)	12 (41%)	15 (50%)	0.81
Marital status[#], n (%)				0.02
Never married	5 (45%)	7 (24%)	11 (37%)	
Married	5 (45%)	20 (69%)	9 (30%)	
Other	1 (9%)	2 (7%)	10 (33%)	
Diagnosis (% disorder)				0.001
Psychotic	2 (17%)	3 (10%)	14 (47%)	
Mood	2 (17%)	9 (31%)	9 (30%)	
Anxiety	2 (17%)	4 (14%)	0 (0%)	
Substance	0 (0%)	3 (10%)	5 (17%)	
Other[^]	6 (50%)	10 (34%)	2 (7%)	
Mean years education (sd)	12 (3.5)	10 (4.3)	10 (3.4)	0.07
Family characteristics				
Relationship, n (%)				0.07
Parent	6 (50%)	11 (38%)	3 (10%)	
Spouse	2 (17%)	6 (21%)	9 (30%)	
Sibling	2 (17%)	7 (24%)	14 (47%)	
Child/other	2 (17%)	5 (17%)	4 (13%)	
Female[#], n (%)	7 (58%)	12 (41%)	18 (62%)	0.32

[a] Data are missing for one participant.

[b] Other diagnoses included adjustment disorder, somatoform disorder, dissociative disorder, sleep disorder and impulse control disorder.

[*] Sites were compared using the Kruskal-Wallis test for age and education and Fisher’s exact test for all other variables.

Table 5

Cross-site comparison of the overall feasibility, acceptability, and clinical utility of cultural assessment from relative's perspective

	Pune (n = 12)	**New Delhi (n = 29)**	**Nairobi (n = 30)**	***P*-value**[*]
Feasibility	1.29 (0.72)	1.28 (0.34)	1.50 (0.37) 1.62	0.15
Acceptability	1.17 (0.78)	1.28 (0.34)	(0.22)	0.01
Clinical utility	1.11 (0.78)	1.09 (0.26)	1.44 (0.35)	0.02
Composite	1.15 (0.68)	1.15 (0.25)	1.48 (0.25)	0.02

Note: data are summarized as means and standard deviation

[*] Sites were compared using generalized estimating equation models that adjusted for clustering by clinician

Table 6

Relative perceptions of the CFI

Categories	Quotes
Positive perceptions	
Explores patient's background	*Asking about beginning of the illness, how long, childhood background – all were useful* (New Delhi, mother) *Asking about childhood injury and tried to get to the bottom of it, and took a detailed history* (New Delhi, sister)
Allows patient to open up, express themselves	*...he doesn 't express all of these things at home; just keeps them in to himself. Because of this questionnaire all these things have come out"* (Pune, wife) *They [CFI questions] give room for the patient to explain himself* (Nairobi, brother) *Good that you asked him about his sadness, he told you all that was in his heart* (Pune, wife)
Helps family understand and change their attitudes	*This allows us as a family to change our attitudes* (Nairobi, brother) *I think the understanding between all three of us was good* (Pune, brother)
Give relative's opportunity to express their opinions	*Even I got to express myself today* (Pune, wife) *This is the first time we were able to spill our guts out* (Pune, wife)
Explore the issues in an in-depth way	*Questions that asked him about his irritation and anger and the reasons for it, were helpful* (Pune, mother) *The questions are deep* (Nairobi, wife)
Negative perceptions	
Questions were difficult to understand	*I am illiterate and am not able to understand properly. First time we have seen such details—filling ups so many forms* (New Delhi, sister-in-law) *Questions were ok but language should have been user-friendly. Layman language* (New Delhi, husband)
Additional areas that should have been addressed	*It [interview] should have been more disease-specific* (Pune, father) *Should ask about physical conditions* (New Delhi, father) *I do think that if a little more detail about the patients' history were asked then it would have been better* (Pune, brother) *They should have asked why she [patient] sometimes says that she wants to die* (Pune, daughter-in-law)