Cultural Context in DSM Diagnosis: An American Indian Case Illustration of Contradictory Trends

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Abstract
Recent revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) increasingly acknowledge the importance of cultural context for the diagnosis of mental illness. However, these same revisions include evolving diagnostic criteria that simultaneously decontextualize particular disorders such as Major Depressive Disorder (MDD) and Posttraumatic Stress Disorder (PTSD). As a result, the DSM reflects a contradictory role for context in psychiatric diagnosis. The case analysis presented here frames the consequences of this contradictory trend for an American Indian woman with a history of DSM-IV MDD and PTSD, whose diagnostic portrait is substantively altered in light of more recent DSM-5 criteria. Specifically, consideration of this respondent’s bereavement-related illness experience suggests that a sociocentric cultural frame of reference, which places high value on interdependent personal relationships, is not well-captured by DSM-5’s revised MDD or PTSD criteria, or the newly proposed categories of traumatic bereavement or Persistent Complex Bereavement Disorder. The respondent’s illness experience argues for greater recognition of this contradictory diagnostic trend, suggesting a need for future resolution of this tension toward more valid diagnosis for culturally diverse populations.

Keywords
Diagnostic and Statistical Manual of Mental Disorders (DSM), Major Depressive Disorder, Posttraumatic Stress Disorder, cross-cultural diagnosis, American Indians, traumatic bereavement

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Introduction

Cultural psychiatry and multicultural psychology affirm the need for mental health providers to consider the sociocultural context for their patients’ experiences. Indeed, continued investigation of and commitment to culturally relevant mental health care continues to shape the mental health professions (Cross, Bazron, Dennis, & Isaacs, 1989; Lie, Lee-Rey, Gomez, Bereknyei, & Braddock III, 2011; Saha, Beach, & Cooper 2008; Sue, Zane, Nagayama Hall, & Berger 2009). Revised iterations of the Diagnostic and Statistical Manual of Mental Disorders (DSM) reflect the proliferation of these ideas. The DSM’s primacy as the text used in the United States to characterize and diagnose psychopathology renders evolutions in the manual noteworthy and impactful.

Thus, examining shifts in the description and application of context in the DSM can shed light on its incorporation into clinical diagnosis. For example, greater inclusion of cultural context has had profound ramifications for the well-being of culturally diverse populations. American Indians (AIs) are one such group, experiencing mental illness, including PTSD, substance use disorders, and suicide at higher rates than the general population (Gone & Trimble, 2012; Jones, 2006). AI contention with histories of colonialism and subjugation demands consideration during clinical interactions (Sotero, 2006; Evans-Campbell, 2008). The following case discussion clarifies the challenge of accurately characterizing a patient’s disabling distress, given opposing trends in recent revisions of the DSM. As we hope to demonstrate, diagnostic attention to cultural context—including associated conceptions of selfhood—may be necessary to validly capture illness experience.

Diverging Trends in the DSM

Consistent with the push for culturally relevant mental health care, recent editions of the DSM increasingly consider patient context via the influence of culture (Ecks, 2016). Such consideration allows one form of contextual consideration—that of cultural variation—increasing influence, even while the opportunity to involve other patient contexts have been removed from some disorders. Context-dependent diagnostic criteria for Major Depressive Disorder (MDD) and Posttraumatic Stress Disorder (PTSD) have been removed between DSM-IV (American Psychiatric Association, 2000) and DSM-5 (American Psychiatric Association, 2013).

Two examples illustrate this trend. One is the much-debated removal of the Bereavement Exclusion (BE) from DSM-5, which had previously limited MDD diagnoses after the death of a loved one (Wakefield & First, 2012; Zisook et al., 2012). The other is the evolution of criterion A for PTSD, which had previously specified the disorder as contingent upon particular responses to a recognizable stressor “generally outside the range of usual human experience” (Brewin, Lanius, Novac, Schnyder, & Galea, 2009).

And yet, there can be little doubt that bereavement and trauma are culturally patterned. Movement toward diagnosis based on further decontextualized
symptom presentation has occurred in some DSM-5 disorders even as attention to the cultural context has simultaneously increased. These contradictory trends send mixed signals to mental health professionals and researchers, with ramifications for the diagnosis of MDD, PTSD and their interface with bereavement, especially for culturally diverse populations.

**Evolution of Culture in the DSM**

In DSM revisions between versions III and 5, cultural context became increasingly prominent (Lewis-Fernández et al., 2010; Mezzich et al., 1999). DSM-IV, published in 1994, employed a broader discussion of culture and its impact than previous editions (Alarcón et al., 2009; Mezzich et al., 1999). A new introductory section entitled “Ethnic and Cultural Considerations” asserted that, “a clinician who is unfamiliar with the nuances of an individual’s cultural frame of reference may incorrectly judge as psychopathology those normal variations in behavior, belief, or experience that are particular to the individual’s culture” (p. xxi). In addition, DSM-IV included new appendices entitled “Outline of Cultural Formulation” and “Glossary of Culture Bound Symptoms” (p. 843) and incorporated descriptions of cultural variations in symptoms for each disorder described.

Language in the introduction to DSM-5, published in 2013, enhanced this framing, describing disorders themselves as “defined in relation to cultural, social, and familial norms and values” (p. 14). DSM-5 highlighted the way “culture provides interpretive frameworks that shape the experience and expression of the symptoms, signs, and behaviors that are criteria for diagnosis” (p. 14). This description recognized culture and individual context as mediators of illness and treatment experience. The DSM-5 included a cultural formulation interview, which, upon investigation, has been shown to improve cultural competence for psychiatry residents (Aggarwal, Nicasio, DeSilva, Boiler, & Lewis-Fernández, 2013; Lewis-Fernández et al., 2014). Culture’s presence in the manual for diagnosis of mental disorders underscores its increasing importance during the decades between the publication of DSM-IV and DSM-5 (Alarcón et al., 2009).

**Evolution of Major Depressive Disorder in the DSM**

While the influence of culture as context increased in recent DSM iterations, this same trend does not hold when considering MDD specifically. Diagnostic criteria for MDD have become increasingly decontextualized (Gold & Kirmayer, 2007; McGrath, 2009). Recent DSM revisions include diagnostic criteria without reference to individual patient experience (Whooley, 2014). Notably, in the introductory section for MDD in the DSM-III-R (American Psychiatric Association, 1987), loss of a loved one (the BE) was used to exemplify contextual considerations. DSM-III-R stated, “this syndrome or pattern must not be merely an expectable response to a particular event, e.g., the death of a loved one” (p. xxii).
Given the cultural grounding of bereavement, this created potential diagnostic challenges as the *DSM* encouraged consideration of cultural context but divorced diagnosis from the meaning of distress (Kleinman, 2012; Paletti, 2007). Considering the meaning of distress is crucial for culturally valid diagnosis even with diagnostic practice that remains agnostic toward etiology. *DSM-IV*, marked the “boundary” (p. 780) between bereavement and MDD at two months, meaning MDD could not be diagnosed within two months of the loss of a loved one. Previously, the *DSM-III-R* provided an exception allowing a diagnosis of MDD only when “the disturbance is not the normal reaction to the loss of a loved one” (p. 219). However, challenges with defining a clinically relevant “normal” response led to adjustments and the eventual removal of the BE (Zisook et al., 2012).

*DSM-5* replaced the BE with a footnote on the same page as the diagnostic criteria for MDD. Justification for this removal cited “the recognition that bereavement is a severe psychosocial stressor that can precipitate a major depressive episode in a vulnerable individual, generally beginning soon after the loss,” and added, “it was critical to remove the implication that bereavement typically lasts only two months, when both physicians and grief counselors recognize that the duration is more commonly 1–2 years” (p. 811). Thus, the elimination of the BE further decontextualized MDD diagnosis by removing one form of contextual consideration from the diagnostic criteria, even while the *DSM-5* incorporated cultural variation in grief and depression elsewhere.

**Evolution of Posttraumatic Stress Disorder in the DSM**

Similarly, revisions of PTSD diagnostic criteria have increasingly limited consideration of the patient’s reaction to traumatic stressors despite the observation that meaningfulness is inherent to the experience of an event as “traumatic” (Waters, Shallcross, & Fivush, 2013). Indeed, it is the perception of an event as traumatic that makes it so (Young & Breslau, 2015). In *DSM-III-R*, PTSD diagnostic criteria characterized qualifying stressors as “outside the range of normal human experience” (p. 247). This required clinicians to judge whether a stressor could precipitate PTSD, implying the ability to validly assess a “normal” human experience.

In *DSM-IV*, such language disappeared because it was determined to be “unreliable and inaccurate” (p. 783). This removal coincided with the trend toward attention to culture in *DSM-IV*, which further complicated the idea of “normal” human experience. Instead, the *DSM-IV* emphasized the importance of the response (i.e., involving fear, helplessness or horror in criterion A2) to the stressor. This formulation shifted again in the *DSM-5* following significant criticism of the *DSM-IV* criteria (McHugh & Treisman, 2007; Spitzer, First, & Wakefield, 2007).

*DSM-5* reorganized PTSD diagnostic criteria into four clusters, removed criterion A2 (requiring “fear, helplessness, or horror”), and narrowed the range of stressors qualifying for PTSD diagnosis to “actual or threatened death, serious injury, or sexual violence” (p. 216). Limiting the qualifying stressors, while also ignoring immediate responses to them, eliminated consideration of a patient’s capacity for
culturally-patterned meaning-making after the event. Such meaning-making is a key aspect of cultural context that is otherwise given increasing emphasis throughout the *DSM* (Calhoun, Hertzberg, Kirby, Dennis, Hair, Dedert, & Beckham, 2012; Gold & Kirmayer, 2007; Whooley, 2014).

The interaction of personal loss and PTSD in the *DSM-5* also warrants analysis. *DSM-5* stressors that do not directly affect the individual rarely qualify. Especially relevant to the case discussed here is that loss of a loved one, if not “violent or accidental” (p. 271), does not qualify under criterion A. This represents a shift from previous conceptualizations of PTSD given that sudden, unexpected death of a loved one became an accepted cause of PTSD symptoms (Barlé, Wortman, & Latack, 2017). This narrower diagnostic scope means that mental illness precipitated by stressors that no longer qualify under criterion A must be classified elsewhere. Propositional diagnoses, discussed in the next section, such as Persistent Complex Bereavement Disorder (PCBD) and traumatic grief gesture toward this challenge, but remain unofficial diagnostic categories.

**Interface of Bereavement and Trauma**

Instances of bereavement and traumatic stress precipitating psychopathology do not always fit neatly into established MDD or PTSD diagnostic categories. The disorders are often comorbid. The line between trauma and grief is an active area of research (Afzali, Sunderland, Teesson, Carragher, Mills, & Slade, 2017; Angelakis & Nixon, 2015). Categories combining the two ideas such as complicated grief, traumatic bereavement, and prolonged grief disorder have been described, though not officially adopted as *DSM-5* disorders. Shear et al. (2011), and Boelen, van de Schoot, van den Hout, de Keijser and van den Bout (2010), argued for “complicated grief” as an identifiable disorder distinct from both MDD and PTSD occurring in a small subset of people who experience bereavement. Stroebe, Schut and Finkenauger (2001), and Barlé, Wortman and Latack (2017), framed traumatic bereavement separately from complicated grief, using circumstances of the death in question to label a reaction traumatic bereavement or complicated grief. Prigerson and colleagues (2009) evaluated the psychometric validity of what they termed prolonged grief disorder and recommended its inclusion in *DSM-5*.

Each of these efforts recognizes that grief can be traumatic and that trauma can precipitate grief in ways that depend on patients’ meaning-making. While it does not include these categories as diagnosable disorders, *DSM-5* presented PCBD in the appendix titled “Conditions for Further Study,” recognizing that the interplay between trauma (an emotional response to a horrific event), grief (an emotional response to loss), and depression (a mood disorder centered on dysphoria and anhedonia) warrants further exploration. Discussion of these issues for PCBD within *DSM-5* addressed the problem of differential diagnosis for PTSD, normal grief, and depressive disorders (p. 791), and explicitly considered issues of cultural context (p. 792). In addition, the proposed criteria for PCBD included the specification with or without traumatic bereavement.
Cultural Configurations of Distress

MDD, PTSD, and Culture

Because culture co-constitutes illness experience, culturally diverse populations may express the distress associated with MDD and PTSD differently (Gold & Kirmayer, 2007; Gone & Kirmayer, 2010; Whooley, 2014). For example, alternative cultural conceptions of selfhood have ramifications for the kinds of experiences that might precipitate psychopathology (Draguns & Tanaka-Matsumi, 2003; Kirmayer, 2007). Egocentric conceptions of self—commonly observed in dominant societies of Western Europe and North America, and reflected in biomedicine and the DSM—focus on individual accomplishments and autonomy. Sociocentric conceptions of self—commonly observed in various societies throughout Asia and many Indigenous communities of North America—focus on interdependence between people, groups, or lineages (Kirmayer, 2007). Individuals from sociocentric societies appear in some instances to experience and express psychiatric symptoms differently than people from egocentric societies, affecting the chain of diagnosis and treatment (Marsella & Yamada, 2000).

Such diversity in the expression of distress may lead to problems in the diagnosis of MDD and PTSD for patients outside of the sociocultural contexts that gave rise to the DSM (Kleinman, 2012; Markus & Kitayama, 1991; Nadkarni & Santhouse, 2012). Thus, understanding illness experience and diagnosing it validly for culturally diverse populations requires sensitivity to cultural context (Aggarwal, Nicasio, DeSilva, Boiler, & Lewis-Fernández, 2013). For example, the particular experiences of many AIs have been shaped by Euro-American settler colonialism and its ongoing legacy. As a group, AIs endure a much less healthy contemporary reality than surrounding populations (Bauer & Plescia, 2014; Hutchinson, & Shin, 2014; White, Espey, Swan, Wiggins, Eheman, & Kaur, 2014). Poverty and discrimination resulting from colonization have yielded psychological distress in this population even as Native America includes a diverse array of distinct cultures and traditions (Gone, 2007; Gone & Trimble, 2012; King, Smith, & Gracey, 2009; Warne & Lajimodiere, 2015).

Thus, consideration of cultural context is important for valid diagnosis. However, as previously discussed, context is treated inconsistently throughout the manual, largely considered in introductory and appended material in DSM-5, with more limited influence on diagnostic criteria.

An American Indian Case Analysis

The contradictory trends outlined earlier complicate the challenge of elucidating boundaries between trauma, grief, and depression in culturally diverse populations such as AIs. In the case presented here, we highlight complexities of an illness experience that may be properly understood only with reference to cultural context. This case illustrates how eliminating context-dependent diagnostic criteria in some parts of the DSM may prevent valid diagnostic portraits for the culturally-diverse patients for
whom the *DSM* aspires to be more relevant. Drawing on one urban AI woman’s reported experiences of grief, trauma, and depression enables us to examine the intersections among these constructs in light of evolving diagnostic criteria in an AI cultural context. Specifically, in the following analysis, we seek to trace the implications of the potential contradictions resulting from shifts in the *DSMs* that decontextualize specific diagnostic criteria even as they promote consideration of cultural context.

**Method**

The case analysis presented in this article is based on an open-ended interview with Lisa (a pseudonym). Lisa was recruited for a study designed to examine diagnostic concordance between the World Health Organization’s Composite International Diagnostic Interview (CIDI; Kessler & Üstün, 2004) and the Structured Clinical Interview for the *DSM-IV* (SCID; Spitzer, Williams, Gibbon, & First, 1992) for 25 AI participants from a large Midwestern city (Gone & Alcantara, 2009). Participants were recruited through one of the 34 urban health programs funded by the federal Indian Health Service (IHS, 2016). These 25 individuals participated in a fully-structured CIDI and a semi-structured SCID, with a subset also completing a third open-ended “reconciliation” interview.

The CIDI and SCID, designed to facilitate reliable *DSM* diagnosis in epidemiological and clinical contexts, respectively, yielded participant diagnoses. The purpose of the reconciliation interview was to contextualize these diagnoses through solicitation of illness experiences. This third interview focused (when appropriate) on discordant diagnoses resulting from the CIDI and the SCID as one avenue of investigating meaningful distress that perhaps resisted *DSM* categories. Study participants were paid $35 for completion of the CIDI, $40 for completion of the SCID, and $45 for completion of the reconciliation interview. This study was approved by the controlling university’s Institutional Review Board.

**Participant**

An interview respondent in the summer of 2009, Lisa, in her late 40s, identified as a member of one of the Haudenosaunee (Iroquois) tribes. She had lived in the same metropolitan area her entire life. She resided with her husband of more than 20 years in the same city as her siblings and much of her extended family. Throughout her life, Lisa sought treatment for various physical and mental health challenges, many of which she attributed to loss of loved ones. Like most Americans seeking mental health evaluation, Lisa did not obtain consultation from a psychotherapist, who might have recognized her relational distress or made a more culturally sensitive diagnosis. Instead, she was diagnosed by non-therapist medical providers, and psychotherapy would not necessarily have been expected to feature in her treatment as less than 35% of people utilizing outpatient mental health care receive psychotherapy in addition to medication interventions. (Harpaz-Rotem, Libby & Rosenheck, 2012; Olfson & Marcus, 2010).
At the time of the interview, Lisa discussed ongoing grief after the passing of her mother three years prior. Lisa’s father had passed three years before her mother. Although she endorsed feeling better than immediately after her mother’s death, she reported that these losses still caused her significant distress. The CIDI and SCID suggested multiple DSM-IV disorders. According to both interviews, Lisa met criteria for specific phobia (lifetime), with onset beginning with a fear of blood and injuries in late childhood; MDD (lifetime); agoraphobia with panic disorder (lifetime), with her first panic attack and fear of social situations also occurring in late childhood; PTSD (lifetime); and alcohol abuse (lifetime), with problems beginning in mid-adolescence (and last reported in early adulthood). In addition, during the SCID, Lisa discussed her diagnosis of Meniere’s disease, and the medications she took to combat associated dizziness and nausea.

The clinician administering the SCID noted that the decade prior to the interview was particularly difficult for Lisa, as she underwent multiple surgeries (e.g., hysterectomy) and lost her parents. The CIDI and the SCID resulted in consistent diagnoses. However, the reported events associated with onset of MDD and PTSD varied between the CIDI and SCID because the two interviews adopt differing strategies for assessing these disorders. For example, Lisa’s CIDI diagnosis of PTSD was based on her report of a sexual assault at age three as the “worst trauma” of her life, whereas her SCID diagnosis of PTSD was based on her brother’s unexpected death when Lisa was age 11 years. Interview variance of this kind is commonplace. There was no evidence of direct contradiction in Lisa’s accounts. Indeed, notably, Lisa’s diagnoses achieved perfect concordance.

Measure

The following analysis is based on Lisa’s reconciliation interview. The reconciliation interview allowed respondents to describe problems in their own words (e.g., through illness narratives), to consider discrepancies between CIDI and SCID diagnoses, and to gather additional contextual information that might inform diagnostic interviewing with AI respondents. The reconciliation interview allowed for extended responses. It occurred in one sitting, beginning with inquiries about the most challenging time in Lisa’s life, and continuing to explore her experience with grief and family loss. The interviewer asked follow-up questions regarding Lisa’s efforts to seek physical and mental health evaluation, effective and ineffective therapeutic strategies, and the opportunities she identified to improve communication between AI patients and healthcare providers.

Procedure

All three interviews were audio recorded within a three-month period at the same Urban Indian Health Organization in mid-2007. Lisa’s CIDI interview occurred in May and was administered by an undergraduate student who had completed the CIDI Interactive Training program and received feedback during mock training.
interviews. It lasted 3 hours and 19 minutes. The SCID, which took place the next month, was administered by a doctoral candidate in clinical psychology, who had completed a semester-long seminar on the topic and demonstrated mastery after interviews with psychiatric patients and non-patients. The SCID lasted 2 hours and 39 minutes. The second author conducted the reconciliation interview later in the summer of 2007 and lasted 1 hour and 15 minutes.

The first author served as the primary analyst of the reconciliation interview. Following a close reading of the interview, the first author revised the transcript for accuracy, yielding 12,196 words and 27 single-spaced pages of text. The first author then undertook a thematic content analysis of the interview (Braun & Clarke, 2006) using the qualitative data analysis software program NVivo (version 11) to code recurring ideas in the interview (e.g., references to experiences after familial loss, or treatment benefits or failures). Analysis of these codes generated a two-level thematic framework.

A descriptive level of specification captured instances in which Lisa spoke about a certain issue or event (e.g., her brother’s death, or her frustration with care she received). An interpretive level of specification grouped codes into themes, an abstraction one step removed from Lisa’s actual responses. This step helped to identify connections between recurring topics. For example, selections in which Lisa spoke of the challenge of her parents’ deaths and selections where she described her role as their caregiver were coded separately at the basic level, but both fell under the same theme of "salient personal losses" at the interpretive level, because her caregiving prior to their deaths increased the depth of loss she felt after her parents’ passing.

For such thematic analysis (Braun & Clarke, 2006), both the in-the-moment decisions of the interviewer and the interpretive judgments of the analyst undoubtedly influence the characterization that follows, but these influences are disciplined by the data and open to (limited) scrutiny by the reader. For example, we quote Lisa at various points throughout this article to demonstrate fidelity to her words, and report frequencies associated with the appearance of interview themes throughout the transcript as a proxy for their salience and importance to Lisa.

**Results**

Lisa recounted physical and mental health challenges throughout her life, which she connected to two instances of familial loss. The first was her brother’s unexpected death when Lisa was age 11. His death resulted from complications from a procedure to treat appendicitis (presumably an appendectomy) from which he was expected to make a full recovery, but he did not return from the hospital. The second was the death of Lisa’s parents when she was in her 40s. Lisa sought psychiatric evaluation for psychological distress that she attributed to grief at various times, frustrated by what she described as physicians’ lack of consideration of options besides medication to address her grief. She found alternative support she deemed more effective than consultation with physicians. We identified four
themes from Lisa’s reconciliation interview that form the basis for our conceptualization of her responses: Designated Traumatic Stressors, Salient Personal Losses, Frustration with Care, and Therapeutic Benefit (see Table 1).

**Designated Traumatic Stressors**

This theme encompasses Lisa’s discussion of the traumatic stressors associated with her PTSD diagnoses in the CIDI and SCID, respectively. During the CIDI, Lisa endorsed sexual abuse at age three as the onset of PTSD. During the SCID interview, Lisa said the loss of her brother at age 11 occasioned the disorder. The perceived ramifications of her brother’s loss featured prominently throughout the interview and she described death of loved ones influencing attitudes throughout her life. When asked in the reconciliation interview about the traumatic stressors she reported, she replied that she had felt more comfortable with the CIDI interviewer, who also identified as Indigenous. As a result, she disclosed her experience of sexual abuse in the CIDI, but not the SCID. During the reconciliation interview, Lisa discussed sexual abuse once, but returned to her brother’s death often.

As always, it seems likely that interviewer characteristics influenced the way Lisa recounted her illness narratives. However, the inclusion or exclusion of her sexual trauma does not discount the importance of the diagnostic contradiction explored here. Given how early in life this sexual abuse was reported to have occurred, it is unsurprising that Lisa did not detail this experience in the SCID or the reconciliation interview, both of which (in contrast to the fixed response categories of the CIDI) would necessitate more descriptive elaboration. Empirical studies place the earliest memories adults recall between three and four years old, and there is evidence that adults remember few events before age seven (Bauer, 2014; Dudycha &

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<tr>
<th>Interpretive Themes</th>
<th>Descriptive Codes</th>
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<tr>
<td>Designated Traumatic Stressors</td>
<td>Brother’s death</td>
<td>5</td>
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<td></td>
<td>Response to loss</td>
<td>22</td>
</tr>
<tr>
<td>Salient Personal Losses</td>
<td>Caregiving</td>
<td>9</td>
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<tr>
<td></td>
<td>Loss of parents</td>
<td>26</td>
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<td></td>
<td>Organizing relationships</td>
<td>21</td>
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<td></td>
<td>Siblings</td>
<td>6</td>
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<tr>
<td>Frustration with Care</td>
<td>Doctors</td>
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<td></td>
<td>Ménière’s</td>
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<td>Medication</td>
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<td>Therapeutic Benefit</td>
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<td></td>
<td>Culturally relevant</td>
<td>10</td>
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<td></td>
<td>Healing</td>
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*Table 1. Coding Framework and Frequency.*
Beyond Lisa’s report that the event occurred, she presumably opted not to interpret experiences based on something remembered vaguely, if at all. Thus, in the following analyses, Lisa’s reported experience of sexual abuse does not feature in substantive detail.

In adhering to Lisa’s interview responses, the remainder of this section examines the ways Lisa believed her brother’s death affected her health. Lisa connected fear of loss and her strong attachment to her parents in adulthood to the loss of her brother when she was 11 years old.

What really did me in was when I lost my brother... And then from that point on, when he died when I was eleven, I just clung to my parents all those years... And that’s why it was so horrendous when I lost both of them.

In addition to this initial explanation, Lisa returned to the specific event of her brother’s death to justify subsequent feelings and actions five separate times throughout the transcript (see Table 1). Lisa thus attached explanatory significance to this episode, saying that her brother’s death was what “did me in,” and traced its impact through future relationships.

In the short term following her brother’s death, Lisa remembered significant behavioral changes.

It started then when I lost him. And I got that agoraphobia. I couldn’t go into places after he died. I couldn’t go out to the stores. I’d start sweating and shaking, and feeling like you’re going to pass out.

Lisa identified her brother’s death as the point when she began “clinging” to her parents, which made their passing more challenging. In addition to MDD and PTSD, Lisa described her anxiety and agoraphobia with panic disorder beginning after this event as a child and continuing up to the interview in her late 40s. She mentioned her psychological and physical response to loss generally, influenced by the loss of her brother specifically, 22 times throughout the interview (see Table 1). Lisa’s formulation of events indicated that a bereavement experience early in life influenced mental health and behavior in the short and long term. This event apparently caused a shift in Lisa’s relational sensibility and ingrained a desire to avoid the loss she associated with her brother’s death.

**Salient Interpersonal Losses**

This theme concerns the ways Lisa discussed her relationships with members of her family and friends and the potential for losing such relationships. During the reconciliation interview, Lisa immediately identified the loss of her parents—her father passed away when she was 40 years old and her mother died three years later—as the hardest time in her life. This followed the CIDI and the SCID interviews during which Lisa indicated that the loss of loved ones precipitated major
depressive episodes and that these episodes interfered with other relationships. In the CIDI interview, Lisa indicated that the loss of her mother had initiated an ongoing episode of depression and additionally that she had at least one depressive episode during 40 of the years of her life. Lisa’s SCID results indicated that she identified her current depressive episode, the one following her mother’s death, as her worst.

As the primary caretaker for both her parents from her early 30s to the time of her mother’s death, Lisa’s days revolved around them. Lisa’s transition to full-time caregiver followed personal medical problems. After taking time off from work to recover from what she described as “sciatic nerve pain,” her parent’s health began failing. Rather than returning to work, Lisa remained a full-time caregiver.

When I lost my job, I just started going to my parents. And then their health started to decline. And I thought, well, I’ll just be there for them. And that’s when I kind of went there and spent as much time as I could with both of them.

While she enjoyed spending time with her parents, she sometimes wished for a day off from these responsibilities. She felt especially isolated after her parents’ death because so much of her time had been spent caring for them. Lisa described herself in her role as a caregiver to her parents in nine separate instances throughout the interview (see Table 1).

Because she spent so much time with her mother and they “went everywhere and did everything together,” Lisa described how she “didn’t really have anyone” besides her husband of 25 years following her mother’s death. Many of Lisa’s friends lived far away and could not provide support. While grateful for their time together, Lisa imagined no end to her distress, and believed that she would grieve for her parents “probably forever.” This showcases the importance of relationships to Lisa’s mental state. Loss of her parents appeared 26 times during the interview (see Table 1).

Even when existing relationships could have helped mitigate the challenges of this situation, Lisa had different ideas about appropriate responses following a loss than her family and siblings.

And then we come out of the funeral home, my brother goes, Do you want to go boating? And I said, I don’t think so…They said, Well, it’ll get your mind off of it. I don’t think anything could console me… I thought my brother and sister, we’d be together to grieve.

Lisa and her siblings’ differing expectations about after her mother’s passing caused tension and led to more anxiety for Lisa. What might have been supportive communication became isolating because her siblings did not share expectations for support after the loss of their parents. For her, the process of grieving did not mean boating or camping. When her closest relations—her
siblings—did not respond as expected, it made the loss more difficult. Specifics about Lisa’s relationship to her siblings appeared six times throughout the interview (see Table 1).

Even before her parents’ deaths Lisa reported considering the potential for loss with every decision. While existing relationships played an important role in Lisa’s comfort and well-being, an associated fear of losing connections impacted her interaction with the world.

I can’t have children. So that was another loss for me… And it’s, Oh, you should adopt, you should foster care. I don’t know if I’d be strong enough… I’m scared to get too close to them. Because I’ll lose them.

Because personal relationships played a defining role in Lisa’s life, potential disruption of those relationships was distressing. Framing the inability to have children as a loss displayed the importance of personal, especially familial, relationships. Creating new relationships made Lisa nervous, as new connections created the potential for loss. Lisa mentioned these negative ramifications of specific relationships 21 times in the interview (see Table 1).

Lisa consistently felt psychologically and physically sick following losses. Immediately after her mother’s death, Lisa’s health declined dramatically. She saw many doctors before being diagnosed with Meniere’s disease. While some days she felt like herself, on the worst days Lisa was confined to her home or even to a bed or couch with dizziness and nausea. She described Meniere’s as potentially resulting from “grieving so much and crying maybe, and the stress of the loss,” thereby considering the possibility that her emotional response to a loss negatively impacted her physical health. She reportedly sought treatment for these mental and physical health problems as both an adolescent and adult.

**Frustration with Care**

This theme represented Lisa’s discussion of treatment she received for physical and mental illness after her brother’s death. Mental health treatment frustrated Lisa throughout her adult life. She found the care she received lacking the personal, relational nature that she had expected. While she sought treatment for depression, agoraphobia, and anxiety intermittently after her brother’s death, she disliked what she perceived as insistence to treat grief with medication. Lisa expressed frustration at her experience with medical doctors on eight separate occasions (see Table 1). Lisa took medication willingly for Meniere’s, but viewed this differently than treatment for depression or anxiety related to bereavement. She strongly desired to avoid what she described as being tranquilized.

Whether or not Lisa benefited from antidepressant or antianxiety medication, she viewed prescribing medication as a time-saving alternative to personalized care for physicians.
Pills, and bye. That’s what I’ve been getting a lot with a lot of these doctors. I can say, I want this, I want that. And I got scripts like this at home that I’ve never filled. [laughs] They just want to send you on your way. That’s what I get from doctors.

Lisa did not associate her symptoms with the need for psychiatric medication and was dismayed by doctors’ repeated suggestions to pursue this route: “I guess I felt like I didn’t need to be there because, you know, Are you hearing voices? No. Nothing like that. Making me feel like you’re really a mental case, you know.” Prescriptions for Xanax, which she took for one year after her father’s death, and then Valium, which she took for two years after her mother’s death, were intended to help, but made Lisa feel foggy and weak.

Lisa decided on her own, two years after her mother’s death, to discontinue antianxiety medication because she “felt a little bit stronger” and “just didn’t need it.” She discussed taking medication (for Meniere’s disease, agoraphobia or MDD) nine times during the interview (see Table 1). After receiving similar suggestions from multiple healthcare providers, Lisa expressed frustration with doctors stemming from her perception that they “just want to send you on your way.” In contrast, she highlighted her feeling that listening to a patient’s wishes and having compassion were the best ways to establish a strong patient–doctor relationship. This advice centered on the meaningful relationships Lisa saw as important to her mental state.

**Therapeutic Benefit**

This theme encompasses Lisa’s reference to treatments she viewed positively, the people who facilitated them, and what she characterized as beneficial. Lisa described two things that helped improve her grief and anxiety. Both involved discussing her grief and other distress in a supportive group context. These experiences did not take place with credentialed mental health professionals who could have provided psychotherapy or other similar consultation. Rather, her descriptions focused on the communal atmosphere of what she described as healing sessions rather than specific treatments.

The first entailed informal gatherings at a friend’s home, which took place before her parents died in her late 30s and early 40s, and focused on mental distress from previous losses.

I came over and we just talked. I just felt comfortable with her… And she had a lot of natural holistic people come into her house constantly, doing different things… Her house is always full of people coming and going… You felt love and you felt… comfortable, like you knew them all your life.

Her discussions with this friend helped Lisa frame “how to look at things,” and she appreciated what she called the “natural holistic” approach, compared to experiences with health professionals who prescribed medication without fully listening
to her concerns. In fact, she returned to the idea of friends as integral to healing eight times, and described this type of relationally-grounded healing 16 times in the interview (see Table 1).

The other beneficial therapy was a more formal healing program for Indigenous people run by an individual from her parents’ tribal reserve in Canada, which she attended one year after her mother’s death. Lisa described herself as “a suburban Indian,” with little knowledge of her tribal community’s traditions when she first attended this “healing lodge.” This program, where participants resided together in dormitories, involved Indigenous ceremonies facilitated by traditional healers, paired with discussion of each participant’s distress.

Recalling her participation at the healing lodge, Lisa focused on its interactive features.

You go in a circle and there we talked about their problems. That really helped me somewhat. I felt really good after I left. But then I came back home and within a month I was right back again to square one and crying all day. Because I’m home alone and my husband’s at work. And I really don’t have anyone to interact with.

Lisa described feeling “wonderful” and “like myself again” after making connections at the healing lodge, where learning about other’s problems in a communal setting helped. Her situation changed, when she returned to isolation at home.

Looking back, Lisa believed that if she “had met more Native American people” during her treatment before and during her parent’s passing, she would have felt better like “at the healing lodge.” She felt shared cultural connection increased coping and comfort. Lisa discussed these benefits in ten separate instances in the interview (see Table 1). Her discussion of treatment further underscored the importance of personal relationships while contending with grief and distress.

**Discussion**

Considering Lisa’s relational sensibility and framing of her story in terms of personal interaction clarifies the challenge of delineating the interfaces of MDD, PTSD, bereavement, and provisional categories like PCBD. Cataloguing the ways that culturally diverse populations experience bereavement-related distress and how those experiences interact with diagnostic categories will be important when considering cultural context in future *DSM* revisions. Lisa’s CIDI and SCID results both identify MDD and PTSD diagnoses, but analysis of Lisa’s reconciliation interview provides insight into the way that Lisa herself understood her own mental distress. Lisa’s discussion of her experience points to the challenge of demarcating pathological experiences (such as MDD) and normal ones (such as long-term bereavement) because of her relational focus.

Lisa framed both challenging moments and supportive interactions in terms of connections with the people involved. She identified her inability to have children
in terms of loss. While disruption of close relationships yielded traumatic experience and disability, supportive interactions provided relief. Because trusting personal relationships organized Lisa’s life, the perception of being brushed aside by a doctor who should be interested in understanding grief appears to have alienated Lisa from services designated to help her. Even Lisa’s suggestions for changes to healthcare offerings for AI patients centered on interpersonal dynamics. Our concern in this article, however, remains diagnosis. Thus, Lisa’s experience illustrates the ways individuals with differing cultural frames of reference may fall through diagnostic cracks even while attention to cultural context features more prominently in certain sections of the DSM.

Relational Conceptions of Selfhood

Harnessing the distinction between egocentric/independent versus sociocentric/interdependent conceptions of selfhood helps contrast Lisa’s illness narrative and CIDI and SCID diagnoses. The mental health professions (as increasingly reflected in the DSM) acknowledge how cultural context affects the expression of mental illness (Draguns & Tanaka-Matsumi, 2003; Lopez & Guarnaccia, 2000; Ryder, Ban, & Chenstova-Dutton, 2011). Configurations of the self contribute to these diverse experiences (Markus & Kitayama, 1991; Marsella & Yamada, 2000). While egocentric conceptualizations of self coalesce around personal history, accomplishments, individualism, and autonomy, sociocentric conceptualizations of self coalesce around families, clans, and lineages.

Biomedicine privileges the individual and egocentric paradigm in seeking information about illness experience and characterizing it (Kirmayer, 2007). Within the literature on cultural psychiatry, conceptions of selfhood have been observed to affect the expression of psychopathology in at least three different ways (Marsella & Yamada, 2000). First, distress itself can manifest differently in different cultural contexts. Second, diagnosis based on decontextualized diagnostic criteria, may fall into a “category fallacy” (Kleinman, 1987), failing to characterize an individual experience in culturally intelligible terms. Finally, the absence of valid diagnosis harbors implications for effective mental health research and practice.

In the context of this case study, it is important to consider the possibility that Lisa’s experiences of distress, seemingly patterned in relational ways, could have been mischaracterized. Indigenous formulations of self are often described as diverging from the egocentric norms of many Euro-Americans (Draguns & Tanaka-Matsumi, 2003; Kirmayer, 2007). Lisa’s narrative—centered heavily on family and other relationships—suggests a sociocentric frame of reference. If Lisa’s configuration of self diverges from that assumed by the biomedical system to which she turned for help, one consequence could be misalignment between the diagnostic formulations of her providers and beneficial therapeutic activities.

Of course, there is no way to be certain from a case study based on our reconciliation interview whether Lisa’s relational orientation originated from Indigenous cultural socialization. Indeed, she overtly indicated separation from visible aspects
of tribal heritage (although self-socialization as shepherded by her reservation-reared parents might be expected to persist even without visible trappings of Indigenous cultural expression). Whatever the origin, it seems evident that Indigenous patients with sociocentric frames of reference could be misdiagnosed. Thus, the possibility that Lisa’s case may be influenced by cultural frames of reference illuminates the importance of resolving such conflicts.

Lisa’s case and the tension it illustrates in the DSM’s evolution, is one piece of a broader discussion about categorizing complex psychopathology. The ICD-11, released December 2018, also includes a formulation of “Prolonged Grief Disorder,” similar to PCBD as proposed in DSM-5 (Prigerson et al., 2009). Chakrabarti, Berlanga and Njenga (2012) discussed the importance of attending to the variety of ways that mood disorders manifest across cultures in the World Psychiatry supplement to ICD-11. Their assessment includes the recognition that diagnostic tools are “embedded in Western psychiatric practice” (p. 29). Such conclusions emphasize the need to recognize cultural variation in symptom presentation, while creating a diagnostic system.

Thus, with the trend toward increasing acknowledgement of culture, and decontextualization of diagnostic criteria, cases like Lisa’s—involving members of sociocentric societies—might fall through diagnostic cracks of DSM-5 or ICD-11.

Pathologies of Grief and Trauma

Outlining cultural effects of configurations of self—and related ideas of loss, mental illness, and psychological distress—is key to adapting DSM diagnoses for culturally diverse populations. Despite the importance of relationships in Lisa’s narrative, and her endorsement of the death of her brother as the stressor that precipitated a DSM-IV PTSD diagnosis, under DSM-5 this stressor would not qualify. Per DSM-5, a family member’s death must be “violent or accidental” to be grounds for diagnosis (APA, 2013, p. 271).

Moreover, DSM-5 proposes acknowledging traumatic bereavement as distinct from other experiences of loss, but again Lisa’s experience would not qualify (Boelen et al., 2010; Zisook et al., 2010; Shear et al., 2011; Stroebe et al., 2001). Specifically, proposed criteria for PCBD in DSM-5 require specification of the presence or absence of traumatic bereavement, which must be “due to homicide or suicide” (p.790). The fact that Lisa’s experiences—previously endorsed as qualifying traumatic events in her CIDI and SCID interviews based on DSM-IV diagnostic criteria—no longer “count” as traumatic for these DSM-5 diagnostic categories raises questions about the validity of the criteria for culturally diverse populations that privilege relationality and sociocentric selfhood.

For example, within a cultural frame of reference wherein selfhood is determined more by one’s relationships, familial loss—even without the qualifiers of homicide, suicide, violence, or accident—might precipitate clinically meaningful symptomatology characteristic of the disorder that DSM-5 intends to describe. As it stands, none of the traumatic stressors Lisa endorsed (with the exception
of the sexual assault at age three, the sequelae of which are unlikely to be recalled accurately enough to be the foundation for valid diagnosis ([Bauer, 2014]) would indicate PTSD or qualify as traumatic bereavement within PCBD.

In contrast, Lisa’s MDD would still be recognized under *DSM-5* criteria, but the diagnosis would now fail to capture the traumatic nature of Lisa’s experience—or any aspects of her attending bereavement, because she would no longer qualify for any additional diagnoses registering the centrality of grief and trauma associated with the relational injuries occasioned by the deaths of loved ones. Thus, Lisa’s case demonstrates the need for sensitivity to culture and context if the mental health professions are to validly assess psychological distress.

Ultimately, despite the attention paid to culture in the introduction and appendices of the *DSM*, cases like Lisa’s may be understood in culturally myopic terms. So long as the inclusion of culture into the *DSM* is concurrently undermined by further decontextualization of diagnostic criteria for specific disorders, valid diagnosis for culturally diverse populations will remain a fraught endeavor.

**Limitations**

As a case study, this analysis is limited in its generalizability. For example, Lisa’s interview does not allow definitive determination of her distress’s cultural grounding. However, considering the diagnostic tensions that arise when applying a cultural frame to Lisa’s illness narrative illuminates issues beyond Lisa herself. The ways Lisa’s experiences interact with *DSM* trends harbors implications for the validity of cross-cultural diagnosis in Indigenous peoples and other sociocentric communities. Of course, factors specific to Lisa’s experience, as interpreted first by her in the interview and subsequently by the authors in this analysis, require acknowledgment that the particulars will not all apply to individuals with similar cultural backgrounds. Finally, this analysis was not tailored to propose immediate revisions to the *DSM* criteria, it fills a gap in the literature by illustrating the impacts of contradictory trends in the evolution of the *DSMs*.

Beyond our focus on these contradictory trends lie a plethora of other nosological issues that require further investigation. Future adjustments to the *DSM* and *ICD* diagnostic paradigms should balance patient experiences alongside clinician judgments with criteria flexible enough to recognize varied experiences across individuals and cultural groups ([Maj, 2013]). As evidenced by the relational grounding of Lisa’s distress, configurations of selfhood have ramifications for identifying the interface of trauma, depression, and bereavement. Further investigation of these questions will afford more valid diagnosis toward improvements for patients from Indigenous and other diverse cultural backgrounds.

**Conclusion**

In this case analysis, we explored the fit of one interview respondent’s illness narratives with *DSM* diagnostic categories. The fact that the experience of this
American Indian respondent appears to have been captured less after evolutions from *DSM-IV* to *DSM-5* illustrates the challenge of employing increasingly decontextualized diagnostic criteria for MDD and PTSD. As all recent editions of the *DSM* have acknowledged, valid characterization of an individual’s distress requires consideration of cultural context. This case suggests the need for further adjustment of diagnostic criteria to mitigate the disconnect resulting from contradictory trends in the treatment of context in *DSM-5*.

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