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A qualitative comparison of DSM depression criteria to language used by older church-going African-Americans*

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ABSTRACT

Objective: Depression in late life is associated with substantial suffering, disability, suicide risk, and decreased health-related quality of life. According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV), a depression diagnosis is derived from a constellation of symptoms that may be described differently by different people. For example, the DSM language may be inadequate in capturing these symptoms in certain populations such as African-Americans, whose rates of depression misdiagnosis is high.
Methods: This study reports the findings from a church-based, qualitative study with older African-Americans (n = 50) regarding the language they use when discussing depression and depression treatment, and how this compares to the DSM-IV depression criteria. Content analyses of the in-depth discussions with African-American male and female focus group participants resulted in a deeper understanding of the language they used to describe depression. This language was then mapped onto the DSM-IV depression criteria.
Results: While some words used by the focus group participants mapped well onto the DSM-IV criteria, some of the language did not map well, such as language describing irritability, negative thought processes, hopelessness, loneliness, loss of control, helplessness, and social isolation.
Conclusions: The focus group setting provided insight to the language used by older, church-going African-Americans to describe depression. Implications include the advantages of using qualitative data to help inform clinical encounters with older African-Americans.

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Introduction

Depression in late life is often chronic and/or recurrent (Schulberg et al., 1998). It is associated with substantial suffering, disability, suicide risk, mortality, and decreased health-related quality of life (Conwell et al., 1996; Hofmann, Köhler, Leichsenring, & Kruse, 2013; Untzer et al., 2000). When depression affects African-Americans, it is usually untreated, more severe, and disabling compared to whites (Williams et al., 2007). Lifetime population prevalence rates of geriatric depression range from 2.3% to15.8% (Ford et al., 2007; Steffens et al., 2000; Weissman et al., 1988; Woodward, Taylor, Abelson, & Matusko, 2013); however, the prevalence of depression in older African-Americans is less established. Rates of depression in African-Americans have varied widely across different samples as compared with other racial/ethnic groups. While some studies show lower rates of depression in African-Americans compared with whites (Aranda et al., 2012; Jimenez, Alegría, Chen, Chan, & Laderman, 2010), others show higher rates (Dunlop, Song, Lyons, Manheim, & Chang, 2003) or no difference at all (Blazer, Landerman, Hays, Simonsick, & Saunders, 1998; Cummings, Neff, & Husaini, 2003).

African-Americans, including older adults, are less likely to receive a diagnosis of depression from a healthcare provider than other racial/ethnic groups (Akincigil et al., 2012; Kales, Blow, Bingham, Copeland, & Mellow, 2000). However, the reasons for this are not clear. Misdiagnosis has been suggested as underlying the lower diagnostic rates by some investigators (Adebimpe, Hedlund, Cho, & Wood, 1982; Jones & Gray, 1986; Strakowski et al., 1997), but not others (Kales, Neighbors, Blow, et al., 2005; Kales, Neighbors, Valenstein, et al., 2005). Another possibility is that misdiagnosis results from differences in the language African-Americans use to describe the experience of depression, as compared to the language employed in standardized clinical diagnostic criteria such as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). For example, some studies suggest that African-Americans describe depression in terms of somatic symptoms rather than as affective or cognitive symptoms (Brown, Schulberg, & Madonia, 1996). It has also been suggested that African-Americans focus more on their physical symptoms and functionality when reporting depressive symptoms (Brown et al., 1996).

Patterns of expressed depression symptomatology among African-Americans (as opposed to the language expressed in DSM) have varied across earlier studies. For example, one study identified three different profiles of depression in an African-American sample: 'the stoic believer,' 'the angry, "evil" one,' and 'the John Henry doer' (Baker, 2001). The 'stoic believer' referred to the patient who cites faith as the reason to not have depression despite the presence of other symptoms, 'the angry evil one' referred to the patient with a change in personality from being nice to being angry and

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irritable persistently, while the 'John Henry doer' referred to the patient who keeps on taking more responsibility to the detriment of their health. In a study of depressive mood problems, African-American patients revealed increased symptoms such as increased hostility and irritability, increased negativism, a tendency to internalize anger, agitation, and greater suicidal threats or attempts as compared to white depressed patients (Raskin, Crood, & Herma, 1975) while others that included other racial and ethnic minorities have noted the impact of language on diagnosis (Alegría et al., 2008).

The church is a common denominator for many African-Americans, and has been a forum for bridging the gap in health care to the African-American community for decades (Chatters, Taylor, Woodward, & Nicklett, 2015; Lincoln & Mamiya, 1990; Taylor, Chatters, & Abelson, 2012). For instance, studies have suggested that attendance at religious services is protective against depression in older African-Americans (Chatters et al., 2008; Chatters et al., 2015; Reese, Thorpe, Bell, Bowie, & LaVeist, 2012; Taylor et al., 2012) and church-based programs have been shown to help reduce racial disparities in medical conditions, including cancer (Kramish Campbell et al., 2004) and HIV (Hatcher, Burley, & Lee-Ouga, 2008). Additionally, the feeling of belonging to a church has been inversely related to suicidal behavior (Chatters, Taylor, Lincoln, Nguyen, & Joe, 2011). Although church-based programs have been shown to positively affect substance-use disorders and its treatment (Schorling et al., 1997; Stahler, Kirby, & Kerwin, 2007), there is minimal data on church interventions for other mental health problems including depression.

While the language used by older African-Americans may contribute to misdiagnosis or delayed diagnosis, to our knowledge, this idea has not been fully explored. There is a need for further investigation into older African-Americans' experiences with depression, particularly how the language used by this group relates to depression criteria, listed in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*. A more focused analysis of the preferred descriptors used by African-Americans to describe their experience with depression could reduce treatment gaps. The purpose of this study was to explore with older African-Americans the language they commonly use to discuss depression. This study reports the findings from an in-depth qualitative examination of the language used by older, church-going African-Americans to describe depression and how this language compares to that used by clinicians whose objective is to make clinical diagnoses based on *DSM-IV* criteria.

Methods

We used focus groups as a way to examine and understand older African-Americans' knowledge, attitudes, and beliefs about depression and depression treatment. Focus group discussions can successfully capture topical complexities through observation of the group interaction and dynamics that help to elicit in-depth thought (Ulin, Robinson, & Tolley, 2005; Watkins, 2012; Watkins & Gioia, 2015). Focus groups can help frame the types of questions that should be asked of participants, as well as allow for question modifications as information needs or evaluations change. Focus groups were thus employed in this study to capture, in detail, the language used by older, African-Americans to discuss depression. Participants provided written informed consent, including permission to audio record, prior to participation, and received a $50 cash honorarium at the end of each focus group. The University of Michigan Institutional Review Board reviewed the materials from this study.

Sample

The sample consisted of older adults who attended three predominantly African-American churches in southeast Michigan. The sample included 21 men (ages 50–87, mean age: 59) and 29 women (ages 51–94, mean age: 67), most of whom were retired. The sample was chosen based on voluntary participation, following verbal announcements from the clergy during a church service, study fliers available in the church, and information provided on request by the research coordinator. Participants were all African-Americans, at least 50 years of age and willing to participate in the discussion. Participants were not evaluated for or asked about a personal history of depression.

Data collection

Two focus groups were conducted in each of the participating churches – one each for men and for women–for a total of six groups. Standard question outlines were used for all groups; participant queries included: (1) their experiences with depression, including common terminologies used to describe depression; (2) their perceptions of depression treatments including therapy and antidepressants; and (3) the role of the church in depression care. The questions were open-ended, such as 'what words or phrases do you or people you know use to describe depression?' and 'how would you describe depression in other people?' Participants were then encouraged to respond and discuss the questions.

The focus groups were led by gender-matched social workers who were members of the research team. The facilitator directed the group discussion by asking predetermined questions and keeping the focus group participants on topic. Further probes and/or clarification, as appropriate, followed each question. The male and female focus groups in each church ran concurrently to prevent discussion or sharing of information between sessions. Each session lasted between 60 and 90 min. The discussions were audio recorded; another member of the research team took observational notes during the session. The audio recordings were transcribed verbatim, and de-identified. Seven members of the research team then analyzed the transcripts and session notes.

Data analysis

We employed classical content analysis to identify the frequency of codes and determine which concepts were most cited throughout the data (Gibbs, 1997; Leech & Onwuegbuzie, 2008; Watkins, 2012). The purpose of this phase of the analysis was to determine broad study themes and the overall impression of the study team. To prepare for the analysis for the current report, the study team worked individually, then collectively to identify relevant and emerging concepts and terminologies (Watkins, 2012; Watkins & Gioia, 2015). We then reduced the coded data in a way that would produce the major themes of the report. We discussed any language and varying terminologies used by the focus group participants and compared them to the DSM criteria. Identified

terminologies were then mapped onto appropriate DSM criteria and agreed upon by a group consensus.

In our interpretation of the results of this study, we were careful to consider the DSM criteria, which focus on a constellation of symptoms. These DSM criteria included *mood symptoms* like sadness and anhedonia; *somatic symptoms* like fatigue, psychomotor, sleep, and appetite changes; and *cognitive symptoms* like guilt, worthlessness, poor concentration, and thoughts of death (American Psychiatric Association, 2013). As per DSM-IV criteria, at least five of these symptoms – including sadness or anhedonia – must be present, and impair functional ability for at least two weeks for a diagnosis of a major depressive episode (see Appendix). The DSM-IV was used during the study; however, review of the DSM-V showed no significant deviation from the DSM-IV criteria.

Results

The focus group participants described depression in a variety of ways and a difference was noted among the different gender groups. For example, the male groups appeared to use different (non-DSM) terms to describe their symptoms as compared to the female groups, most of whom used terms similar to DSM depression. In both groups, the use of exact DSM terminology was noted intermittently, however, a variety of alternatives to the DSM terminology appeared to be synonyms of the DSM symptom cluster for depression. The language used by the participants focused primarily on the possible causes of depression and its impact on functionality, more so than the symptoms themselves. This was especially noted with worthlessness and anhedonia.

While some words used by the participants mapped well onto the standard criteria, some of the reported language from our study did not map well onto the current DSM criteria. These include language describing irritability, negative thought process, hopelessness, loneliness, loss of control, helplessness, and social isolation (Table 1). Other words used by the participants could be suggestive of more than one symptom included in the DSM criteria, these include words like 'mean', 'agitated', or lethargy, which could refer to mood changes or psychomotor changes. Below, we organized our results based on the symptoms that were most often discussed by the participants: sadness, fatigue, worthlessness, and poor concentration, and thoughts of suicide. Finally, we discuss how the participants linked depression to spirituality, in the context of their church membership.

Sadness

Both the men and women participants discussed sadness often, and described it using terminology in the DSM criteria, as well as alternate phrases that seem to reflect sadness. Alternate phrases that were used included 'feeling down' having 'the blues,' 'tired,' and feeling 'stressed out.' For example, when asked to describe what comes to her mind when she hears the word 'depression,' a 51-year-old woman said:

> I believe that what comes to my mind is a person who is sad, and feels like giving up, and things just not going well for them, you know, and they're constantly unhappy.

Conversely, anhedonia was described using non-DSM-like language. By definition, anhedonia is a psychological disorder characterized by a lack of pleasure derived from an activity that was previously enjoyed. Not surprisingly, the focus group participants discussed their experiences of 'lacking pleasure' without ever using the word 'anhedonia.' Instead, they used terminology such as experiencing 'deviation from the normal routine,' or feeling 'zoned out,' 'being in a funk,' and noticing their 'lack of a great spiritual life.' Anhedonia was described by the participants and associated with the perception of a decline in an individual's functional ability.

Table 1. Terms used to describe depression by male and female participants.

DSM criteria	Female	Male
Sadness	Sadness; down; constantly unhappy; crying; having a pity- party	Feeling down; talking down; the 'blues'; unhappy; sad; feeling destitute; bummed out; out of it; stressed out.
Anhedonia	Loneliness; isolation; not wanting to socialize; withdrawing from doing things; deviate from normal routine; lack of a great spiritual life	Self-neglect; lacking fellowship; loneliness; isolation; no one cares; withdrawn; closing down; zoned out; shut down; locked down; like a fixed stare; unwilling to communicate; low emotional; psychological or spiritual state; everything is mundane; no joy in regular activities; turned off internally; lose the zeal for life; not wanting to be involved in things people are capable of.
Decreased appetite/ weight loss	Not mentioned	Not wanting to eat.
Insomnia or hypersomnia	Not mentioned	Stay in the bed; sleep a lot.
Psychomotor agitation or retardation	Mean; grumpy; inconsiderate; frustration; anger; moody; upset; nervous breakdown; lethargic	Feeling of despair; out of control; cannot seem to slow down enough; misdirected aggression; agitated; lash out at people, worrying; being troubled.
Fatigue/loss of energy	Achiness; tired; fatigued; lethargic; not operating at full strength	Fatigue with no reason.
Worthlessness/ excessive guilt	Worthless feeling; inability to do the things you want or need to do; low self-esteem; lacking something; in a 'funk'; feeling unclear and limited; cannot get through; having insurmountable problems.	Cannot accept criticism; just cannot get it together; regretful; guilt ridden; unmet expectations; do not feel good about events; saturated by disappointment; doubts with self-worth; do not have anything to give to yourself or others; funk; low self-esteem; do not believe in self; fear of unknown; locked up inside; worthlessness; not believing in one's self; helpless; cannot cope anymore; burdened with responsibilities.
Poor concentration/ indecisiveness	Having negative thoughts; seeming overtaken by problems.	State of mind with negative connotations; narrow-minded; like a runaway train through life; poor decision-making.
Thoughts of death	Hopelessness; giving up; suicide; do not want to live anymore.	Give up on life; quit; contemplating suicide; and losing desire to live; give up; not wanting to deal; do not see anything in the horizon; loss of hope; world has caved in.

Fatigue and psychomotor changes

The focus group participants described depression using words like 'mean,' 'grumpy,' 'inconsiderate,' 'frustration,' 'lethargic,' and being 'troubled.' These words could be reflective of mood or psychomotor or cognitive changes. Fatigue was described, and this word choice seemed aligned with what is described in the DSM. For example, a 55-year-old man stated:

> I've seen it also where they become lethargic. You know, they just, kind of just here, they're lazy, lazy in the sense of just not wanting to do anything, not want to keep their hygiene up, not want to eat, not want to go out, all of those things

Similarly, a 54-year-old man provided imagery to describe his experiences that seem to suggest fatigue associated with depression. He noted:

> … it's almost as if a switch has been turned on or turned off internally, depending on how you want to look at it, where you used to be full of energy, now you're lethargic. Where you used to have the zeal to do things and now all of a sudden you don't want to, and depending on which way you look at it, it's as if there's a part of you that has been pulled out or shut down.

Overall, we found that the descriptions of fatigue and the psychomotor changes that the participants described included several words that would suggest a more general depressive symptomatology.

Worthlessness and poor concentration

The focus group participants used terminology such as 'funk,' 'feeling unclear' and 'limited,' and feeling 'saturated by disappointment,' not having 'anything to give to yourself or others,' and not believing in oneself, having a 'fear of unknown,' or feeling emotionally 'locked up inside.' These terms seem to reflect a sense of worthlessness. The participants also used DSM-specific terminology to describe their understanding of the worthlessness and/or excessive guilt that is associated with depression. A 54-year-old male describes this stating:

> You'll see a person that may not want to be involved and you know they have capability of doing certain things, but don't have that belief in their selves anymore.

Poor concentration is a symptom of depression that is specific to an individual's cognition and perception. The participants described poor concentration using terminology that was not aligned with the DSM. For example, phrases such as 'having negative thoughts,' and being 'narrow minded,' were used to describe their experiences with depression. These terms seem to suggest a loss of mental flexibility. Similarly, poor decision-making was used synonymously to describe just how challenging it was to concentrate on things when depressed.

Thoughts of death

The DSM suggests that suicidal ideations or preoccupations are cognition and perceptual symptom styles. The focus group participants believed that thoughts of death were noteworthy symptoms of depression, as they mostly described such behavior using DSM terminology.

For example, a 63-year-old man simply stated that experiencing depression was akin to feeling as if he '…lost all hope' and was '… contemplating suicide.' Other participants appeared to describe suicide with words such as 'hopelessness,' 'giving up,' and 'don't want to live anymore.' Thoughts of death were acknowledged to signify an extreme form of the disorder and also an inevitable consequence of untreated depression.

Linking depression to spirituality

Many focus group participants believed that if they were affiliated with a church, then their likelihood of experiencing depression would decrease. In some of the groups, depression was determined to result in decreased spirituality, or 'lacking fellowship' with God and others. For example, a 51-year-old woman lamented:

> I also have seen areas where people that are depressed, most likely the people don't have a great spiritual life because when you have a great spiritual life, it gives you that ability to rise above no matter what// they deviate from the normal routine like bathing or cooking effects, you know, just don't even change clothes, then you know something's wrong.

The participants also reported prayer and faith as a first line of defense to address depressive mood symptoms, and prevent progression to more severe symptomatology.

Discussion

This study reported the findings from an in-depth examination of the language used by older, church-going African-Americans to describe depression. Our findings determined that while some languages used by older African-Americans to describe depression were similar to some DSM criteria terminology, specific words used to explain the symptoms were different. In previous studies, older adults have reportedly presented more somatic symptoms compared to younger adults (Adebimpe, Hedlund, Cho, & Wood, 1982; Hegeman, Kok, Van Der Mast, & Giltay, 2012). In the sample, the female and the male groups described more cognitive and behavior symptoms; limited spontaneous description of somatic symptoms except fatigue and sleep.

Appetite change and excessive sleep were mentioned, only in one instance as a potential symptom of depression. None of the participants cited physical ailment as a symptom of depression. We did not anticipate this finding. It is possible; however, that while these symptoms may very well be present in depressed older African-Americans, they may fail to report or not recognize these as related to their depressive mood. The somatic symptoms may be attributed to other causes, including being part of normal aging, inadequate rest, or medical illnesses. This may be due to limited knowledge of depression, and contributes to the higher rate of misdiagnosis in the population. It is also possible that mild depression characterized by sleep and appetite changes is often missed for early treatment, leading to the severity of mood symptoms observed when depression is eventually diagnosed in this group. Misdiagnosis of depression in early and more treatable stages is likely contributory to the reduced likelihood of seeking formal care for depression by older African-Americans. More education about somatic symptoms as part of a depressive mood syndrome may need to be provided to this population.

Some of the reported language from our study did not map well onto the DSM-IV criteria. These include language describing irritability, negative thought process, hopelessness, loneliness, loss of control, helplessness, and social isolation.

Despite this, our exploration of African-American church member focus group responses may compare to the DSM-V criteria for depression. While these are commonly reported symptoms in older adults – some of which can be elicited by current rating scales including the Geriatric Depression Scale – they are not included in the DSM-IV criteria. The participants placed emphasis on the degree of functional impairment. This suggests that even if symptoms of depression are present, if the impact on functionality is not severe, it may not be acknowledged as a disorder that merits an evaluation or treatment. The latter could contribute to the severity of depression seen in this population. Inquiries about attitudes toward life and the ability to function at an optimal level may reveal more information about depressive mood symptoms in older, church-going African-Americans. It is notable that men had more descriptive words for depression symptomatology most notably with worthlessness and anhedonia. This may be related to the impact of these symptoms on the functional ability and their sense of identity.

Another potential factor to delayed diagnosis may be the belief that being spiritual should eliminate depressive symptoms. This is in agreement with prior work that found an association with church attendance and less depression particularly with African-Americans (Chatters et al., 2008; Chatters et al., 2015; Taylor et al., 2012; Watkins, Wharton, Mitchell, Matusko, & Kales, 2015). However, the delayed diagnosis that may present itself among African-Americans, may lead to progression to more severe symptomatology. It is important to interpret these findings in the context of the environment in which they were collected and analyzed: the black church. In some churches, the participants were aware of depression; being in the church setting did not appear to alter the participants' views of depressive mood problems. Conversations seemed to be guided more by non-clinical than clinical experiences with depression. During the discussions in the different churches, there were discussions about depression in the church, the groups that mentioned endorsement by the pastor of this being a problem, were more open to discussing their personal experiences, while the others focused more on not having a 'spiritual' life being the cause of the depression. When the members of a particular church were more open to discussing depression freely, these participants felt more at ease in describing their personal experiences or experiences of those close to them who were depressed.

This study reported on the findings from an in-depth qualitative examination of the language used by older, church-going African-Americans to describe depression as it compares to the language used by clinicians with whom they are most likely to interact in primary care settings. The findings from this study have implications for mental health care in the African-American community and ways to think about care that targets their cultural needs. These cultural needs will need to consider the implications of the church and religious involvement among older African-Americans (Chatters et al., 2008; Chatters et al., 2015; Taylor et al., 2012) as well as the specific implications that this has with regard to gender differences among older African-Americans.

Limitations

Our findings should be interpreted in the context of a few limitations. For example, this was a voluntary sample, likely giving rise to a selection bias, both with the churches and the individuals who participated in the study. We understand that the church members who were full and active participants in our study may have been more aware of depression and its symptoms; and therefore, more motivated to participate. These individuals may have been more open or more aware of depression than others. Also, there are certain limitations that the study design may render. For example, focus groups may limit full disclosure and articulation of individual perspectives. Also noteworthy is that the focus groups were held in similar churches and may not be a reflection of language used in other denominations. Finally, while an incentive was helpful in recruiting participants, it may also create a bias in the responses provided. Despite its limitations, this study will help clinicians move toward more accurate depression assessment strategies for community-dwelling African-Americans.

Conclusion

It may be more important to specifically focus on the potential impact of depressive mood symptoms on functional ability rather than on reported symptoms themselves as outlined in the DSM-IV-TR in diagnosing depression in this population. There may also be the need to educate this population about the various symptoms of depression, including somatic symptoms. The focus group setting provided insight to the language used by church-going African-Americans to describe depression and how this can be better explored to aid in the diagnosis of depression in church-going African-Americans, and potentially improve early diagnosis, formal treatment, and reduce the severity of symptoms previously documented in the older African-Americans, both in the church and in the community as a whole.

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Appendix. DSM-V criteria for a major depressive episode

Note: This is not a codeable disorder.

A. Five (or more) of the following criteria have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure. *Note:* Do not include symptoms that are clearly due to a medical condition.

(1) Depressed mood most of the day, nearly everyday, as indicated by either subjective report (e.g. feels sad or empty) or observation made by others (e.g. appears tearful). *Note:* In children and adolescents, can be irritable mood.

(2) Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly everyday (as indicated by either subjective account or observation made by others).

(3) Significant weight loss when not dieting or weight gain (e.g. a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly everyday. *Note:* In children, consider failure to make expected weight gain.

(4) Insomnia or hypersomnia nearly everyday.

(5) Psychomotor agitation or retardation nearly everyday (observable by others, not merely subjective feelings of restlessness or being slowed down).

(6) Fatigue or loss of energy nearly everyday.

(7) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly everyday (not merely self-reproach or guilt about being sick).

(8) Diminished ability to think or concentrate, or indecisiveness, nearly everyday (either by subjective account or as observed by others).

(9) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning *(Language regarding 'impairment' may change for consistency with DSM-IV conventions)*.

C. The episode is not due to the direct physiological effects of a substance or antidepressant intervention (e.g. a drug of abuse, a medication, or other treatment). Note: A full hypomanic or manic episode emerging during antidepressant treatment (medication, ECT, etc) and persisting beyond the physiological effect of that treatment is sufficient evidence for a hypomanic or manic episode diagnosis. However, caution is indicated so that one or two symptoms (particularly increased irritability, edginess, or agitation following antidepressant use) are not taken as sufficient for diagnosis of a hypomanic or manic episode.