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Describing depression: Congruence between patient experiences and clinical assessments

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Abstract

Objectives—Efforts to describe depression have relied on top-down methods in which theory and clinical experience define depression but may not reflect the individuals' experiences with depression. We assessed the degree of overlap between academic descriptions of depression and patient-reported symptoms as conceptualized in the Patient-Reported Outcomes Measurement Information System® (PROMIS®). By extension, this work assesses the degree of overlap between current clinical descriptions of depression and patient-reported symptoms.

Design—In this content analysis study, four focus groups were conducted across two sites to elicit symptoms and the experience of depression from depressed and medically ill patients.

Methods—Depressed and medically ill patients were asked to describe symptoms that characterize depression. Data were transcribed and then coded using an *a priori* list of 43 facets of depression derived from extant depression measures.

Results—Participants described 93% of the symptoms from the *a priori* list, supporting the validity of current depression measures. Interpersonal difficulties were underscored as was anger. In general, results from the focus groups did not require the generation of new items for depression and supported the content validity of the PROMIS hierarchical framework and item pool created originally.

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Conclusions—This work supports the validity of current depression assessment, but suggests further investigation of interpersonal functioning and anger may add to the depth and breadth of depression assessment.

Conventionally, nosologies such as the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed., text revision (DSM-IV-TR; American Psychiatric Association, 2000) have been developed by expert researchers and clinicians in diverse areas of mental health practice (Blashfield, 1998). Although informed by extensive research and clinical experience, the generation and selection of symptoms that describe depression and direct its assessment have been driven by theoretical, top-down approaches. The extent to which the resultant symptoms and constructs of depression overlap with individuals' experience of depression has yet to be formally validated. Without a bottom-up confirmation of the field's understanding and assessment of depression, it is impossible to know if some symptoms are overemphasized, underrepresented, or overlooked entirely. The present paper aims to explore the degree to which the patient experience and clinical assessment of depressive symptoms overlap.

With diagnostic criteria changing over the past 25 years (American Psychiatric Association, 1952, 1968, 1980, 1987, 1994, 2000), there is considerable diversity in the symptoms included across depression assessments. Table 1 illustrates the varying depressive symptoms included in commonly used interviews and self-report measures. Given this variability, it is valuable to assess which aspects of depression are most salient from the patient's perspective. Individuals who have suffered from or are prone to depression are important resources regarding the types of symptoms that serve as prodromal signs of the onset of depression and have the greatest impact on individual functioning. The patient perspective may provide researchers and clinicians with improved assessments that more fully capture patients' experiences and offer new inroads to effective treatment and prevention of depressive episodes, and might provide insight into the relationship between specific symptoms and recovery.

Study aims

The current study was part of the Patient-Reported Outcomes Measurement Information System® (PROMIS®) project, an ongoing National Institutes of Health (NIH) Roadmap Initiative. PROMIS seeks to develop brief assessments of patient-oriented outcomes for use in clinical research that cross several domains of well-being that are applicable across diagnostic categories (see www.nihpromis.org; Cella *et al.*, 2007; DeWalt, Rothrock, Yount, Stone, & PROMIS Cooperative Group, 2007; Reeve *et al.*, 2007). One focus area for PROMIS is negative affect, including depression. Because of the emphasis on patient reports, PROMIS is collecting patient feedback on assessment development through several avenues including the use of focus groups. We conducted patient focus groups on depression in order to achieve three aims: (1) to capture a wide range of the spectrum of depression experience from lower to high threshold depression symptoms; (2) to perform content analysis to describe the degree to which current theoretical and clinical assessments of depression overlap with patient-reported symptoms; and (3) to assess the content validity of the PROMIS depression item bank from a patient perspective.

Methods

Dimensional nature of depressive symptoms

Sample—One PROMIS goal is to develop patient-reported outcome measures that are relevant across the normal to pathological spectrum. The PROMIS assessments are intended to provide health status profiles applicable across a wide range of health conditions rather than being disease specific. PROMIS item banks provide a dimensional assessment of the severity of health conditions and are not intended to be a screening or diagnostic tool. Scores across all 11 PROMIS item banks currently available – physical functioning, pain, fatigue, emotional distress, sleep and wake disturbance, and social participation – can be derived with the administration of just a few items (in most cases, 4–6 items using computerized adaptive testing), making them practical to implement in both clinical and epidemiological contexts.

Because of our interest in capturing depression across the spectrum of experience, we sought focus group participants who would likely vary in the severity of their depressive symptoms. In order to capture our intended dimensional range of depressive symptoms (mild to severe), we conducted focus groups with individuals receiving speciality mental health treatment and a sample of medically ill individuals (Barrett, Barrett, Oxman, & Gerber, 1988; Kirmayer, Robbins, Dworkind, & Yaffe, 1993; Lépine & Briley, 2004; Patten, 2001). Rates of depression and depressive symptoms increase as one moves from community-based populations to primary care and speciality medical populations. For example, in clinical epidemiologic studies of patient populations seen in speciality medical settings (e.g., patients receiving care for cancer, lung disease, heart disease, etc.), the point prevalence rates of major depression range up to 60% (Dew, 1998; Katon, 2003). Thus, we felt that including medically ill individuals would provide a sample likely to have mild to moderate depressive symptoms and would afford us the opportunity to characterize symptoms of depression as they occur across the normative to pathological spectrum.

Twenty-nine adults participated in the study across four focus groups. Participants included 13 psychiatric out-patients diagnosed with major depression and 16 general medical patients. The sample was 48% women (N = 14), 48% minority (N = 14), and 45% married (N = 13). Forty-five per cent of the sample had at least a college degree (N = 13), and the sample mean age was 54.6 years (SD = 11.4). Focus groups ranged in size from 6 to 8 participants. Participant demographic information can be found in Table 2. The local Institutional Review Boards approved this research. Participants signed informed consent forms at the respective institution.

Psychiatric participants: Two groups of depressed individuals were recruited from an adult out-patient psychiatric clinic at Western Psychiatric Institute and Clinic in Pitts-burgh, Pennsylvania, USA. Individuals were recruited through a research registry of clinic out-patients who consented to be contacted for research participation. We queried the registry database to identify individuals with a depressive diagnosis confirmed through medical records who did not have active substance dependence, schizophrenia, or bipolar disorder. Of the 384 individuals meeting these criteria, a sample of approximately 50 registry participants was selected for balanced demographic characteristics. These individuals were mailed a recruitment letter. Respondents were screened to confirm that they were currently receiving mental health treatment, had experienced symptoms in the past month, and were not diagnosed with schizophrenia, bipolar disorder, or active substance dependence. Just prior to focus group participation, a second medical record review confirmed that all participants in the depression groups were diagnosed with major depression. Moderator summaries following the focus groups indicated that participants also mentioned having the following chronic medical conditions: sleep apnea, high blood pressure, heart transplant recipient, arthritis, fibromyalgia, and cancer.

Medical participants: The two groups of medical out-patients were recruited from clinics treating cardiovascular and mixed general medical patients at the Duke University Medical Center, Durham, North Carolina, USA. Data collection for the Durham groups was performed by Johnston, Zabor, McManus, Inc. (JZM). JZM, a marketing research firm located in North Carolina, is a member of the Council of American Survey Research Organizations and adheres to the Council's Code of Standards for confidentiality in research (see http://www.casro.org/codeofstandards.cfm). The company has extensive experience identifying, enrolling, and interviewing populations across the USA.

JZM identified potential participants via an existing database of 4,000 medical patients who had consented to be contacted by JZM to participate in research. JZM queried the consumer registry database to identify individuals who reported a medical condition and recruited a representative sample of individuals based on age, gender, race, income level, and education. Eligibility screens were completed to obtain background information and confirm active treatment for a medical condition in the past month. Medically ill participants in the Durham groups were not required to have a specific psychiatric diagnosis and were not required to be in psychiatric treatment. However, moderator summaries indicated that all members of the medical condition groups endorsed state-like feelings of sadness and frustration. Ten of the sixteen also endorsed more chronic negative affect including worthlessness and hopelessness.

Measures—Participants completed the Center for Epidemiologic Studies Depression Scale (Radloff, 1977), a brief, self-report scale assessing depression. The Center for Epidemiological Studies – Depression Scale (CES-D) was developed as an epidemiologic assessment of depressive symptom severity for use in the general population (Radloff, 1977). Item content includes depressed mood, hopelessness, worthlessness, disturbed sleep, poor appetite, and difficulty concentrating among others. Since its development, the CES-D has been widely used to assess depressive symptom severity among both the general population and among psychiatric populations. The CES-D also has a significant record of use among individuals with medical problems such as chronic pain, cancer, and epilepsy, where it demonstrates good psychometric properties including specificity and sensitivity (see Hann, Winter, & Jacobsen, 1999; Jones *et al.*, 2005; Turk & Okifuji, 1994). The measure consists of 20 items scored on a 0–3 scale with a possible range of 0–60. Higher scores indicate greater depressive symptom severity. CES-D total scores of 16 or more are considered indicative of clinically significant symptoms of depression (Ensel, 1986; Wellisch & Lindberg, 2001). The mean CES-D score in the psychiatric group was 20.5 (*SD* = 11.99), indicating moderate depression. The mean for the medical condition group was 10.3 (*SD* = 9.1), reflecting more mild symptoms of depression and supporting our goal to include individuals across the depression spectrum.

Focus groups—In an effort to limit the idiosyncrasies that might emerge in terms of regional differences, differences in psychiatric or medical diagnosis, depression level, and facilitator style, we conducted two focus groups at each of two sites. Our overall goal was to select a diverse sample of medical and psychiatric patients in which to compare our *a priori* hierarchical structure of depression with patient-reported symptoms.

After a review of the literature and consultation with both content and qualitative methodology experts across the PROMIS network, semi-structured scripts were written for the focus groups. Moderators used these scripts to elicit group participation and discussion of specific topics. Open-ended probes focused on: general depressive symptoms; describing depression to others; recent symptoms experienced; symptoms that most impacted function; and how depression affected relationships (see Appendix). Participants largely spoke of their own depression but occasionally commented on their experiences with depressed loved ones. Facilitators adopted a supportive, non-directive, and non-evaluative stance. They emphasized group confidentiality and explicitly stated that group consensus was not required and that individual contributions were valued. Focus group sessions were recorded, transcribed and de-identified. The transcripts were coded and analysed using ATLAS.ti (Muhr & Friese, 2004).

Qualitative data analysis

Code development: As part of the larger PROMIS study, an extensive survey of extant measures of depression was conducted. The measures were reviewed by experts who sorted and categorized them into key themes, resulting in 43 distinct categories of depression symptoms (see Table 3). This hierarchical structure represented an *a priori* set of codes that were fully defined and were used to categorize focus group data. The construction of the item banks and hierarchical structure is described in greater detail elsewhere (DeWalt *et al.*, 2007).

The University of Pittsburgh's Qualitative Data Analysis Program (QDAP) assisted with data analysis. Two investigators, each with over 5 years of clinical experience assessing and working with depressed individuals, served as coders (M. A. R. K. and T. H.). Using the PROMIS hierarchical structure as a framework, coders assigned appropriate conceptual categories to the fewest number of complete sentences that captured the each thematic concept or symptom being described. Coders were instructed not to infer participants' meaning or intent. On some occasions, the unit of text coded was one word (e.g., 'hopeless') but more often it was one or more sentences (e.g., 'But a lot of anxiety. It's like waiting for the other shoe to fall'). Coders were permitted to assign more than one code to each sentence or passage if more than one concept was described. Examples include: 'sadness and anger' (coded 'sadness/depressed affect' and 'anger'), 'It depends, sometimes too much sleep, sometimes not enough' (coded 'general sleep disturbance' and 'excessive sleep').

Data coding was performed using an iterative approach. After preliminary coding of the first transcript, weekly consensus meetings were convened to add or revise codes, clarify code definitions, and review rater agreement. The consensus group consisted of two coders, two members of the PROMIS research staff (one of whom is a trained clinical psychologist) and a data analysis technician from QDAP. Preliminary estimates of inter-rater agreement were generated for each conceptual category. For consensus purposes, we considered $\kappa \geq .60$ to be acceptable. For conceptual categories with suboptimal agreement ($\kappa < .60$) discrepancies were resolved through consensus. In this process, each passage which was ascribed to a category with low agreement was reviewed by the group. Where discrepancies in coding were discovered, each coder discussed her rationale for assigning the code or codes she assigned. Members of the consensus team then discussed coding options and arrived at a consensus for the passage in question. Coders occasionally agreed to disagree following discussion. This most often occurred when one coder wanted to include supplementary codes beyond the principal or secondary codes while the other did not.

Coders also discussed how to rate text that was salient to the experience of depression but did not fit into existing conceptual categories. If a symptom could not be appropriately coded into one or more of the conceptual categories, coders were instructed to assign a code labelled 'other'. These 'other' code quotations later served as a check of the comprehensiveness of the hierarchical structure, that is, if patients mentioned novel symptoms, the conceptual category structure could be expanded.

Transcript review was an iterative process, in that text previously reviewed could be re-coded as needed so that all coding conventions were uniformly applied across the four transcripts. Coding decisions were transferred to each coder's individual documents either during or soon after each consensus meeting. Once final coding decisions were documented on all four transcripts, files from each coder were merged into a single document. Redundant codes (text where both coders applied the same code) were removed, resulting in a single file for final analyses.

This iterative consensus approach was similar to coding approaches used in psychology and psychiatry, whereby an individual or individuals code information and then present it to a group, which then adjudicates until a consensus code is obtained. For example, consensus approaches are commonly used to rate life-events in the Bedford life-events and difficulties schedule (Brown & Harris, 1978) and to make comprehensive clinical judgments using best estimate decision making (Spitzer, 1983). Further, this style of coding and code revision via consensus is commonplace with focus group analyses. While it is not as amenable to traditional replication and reporting of inter-rater reliabilities, it allows for more comprehensive and dynamic description of the data collected than would a static, independent data analysis plan.

To confirm the code assignments that were made, a third coder was recruited to independently code all four transcripts. Brief training, consisting of 1 h in person, 30 min via phone and brief written instruction, was conducted so that the third coder would be familiar with the coding conventions used in the first coding effort. The coder (E. B.) was a doctoral student in clinical psychology with significant experience in depression assessment. Transcripts were provided indicating the passages that were previously coded by the consensus group but with codes omitted. These transcripts were then recoded by the third coder so that we could assess reliability. Kappa statistics were calculated for codes that were assigned at least 10 times across transcripts in the initial coding effort (excluding the ‘other’ code) and an overall kappa score was calculated.

Results

Hierarchical structure and endorsement

The vast majority (93%) of conceptual categories in the *a priori* hierarchical structure were mentioned by participants. The three conceptual categories not mentioned by participants were ‘poor mood distinct from grief or loss’, ‘troubling dreams’, and ‘somatic arousal’. In several instances, participants reported broad concepts associated with these symptoms, but did not endorse the specific conceptual category. For instance, many participants described feelings of grief, but did not explicitly describe their feelings of depression as distinct from grief. Similarly, with regard to somatic arousal, some participants endorsed anxiety, nervousness, or worry about the future but did not report specific somatic symptoms (e.g., sweating, increased heart rate). Of interest, this is in line with the tripartite model of anxiety and depression which allocates somatic arousal exclusively to anxiety while the emotional experience of anxiety shares variance with depression (Watson *et al.*, 1995).

The most frequently endorsed *a priori* conceptual categories were ‘sadness/depressed affect’, ‘interpersonal alienation or sensitivity’, ‘interpersonal conflict’, and ‘social withdrawal’ (see Table 2). While most quotes (64%) only had a single conceptual category assigned to them, 36% were assigned to two or more conceptual categories. The average number of conceptual categories assigned to each quote was 1.53 (*SD* = 1.03).

A posteriori conceptual categories

To capture emerging symptom-related themes that were not well accounted for in the *a priori* hierarchical structure, nine conceptual categories were added during the consensus coding process: ‘anger’, ‘anxiety’, ‘paranoia’, ‘regretful rumination’, ‘substance use’, ‘alexithymia’, ‘avoidance’, ‘emotional pain’, and ‘amotivation’. Table 4 presents example quotes from each of these *a posteriori* conceptual categories.

Although ‘irritability’ was an *a priori* conceptual category, the concept often failed to characterize the intensity of anger that participants expressed. Of the *a posteriori* symptom-related conceptual categories, ‘anger’ (including any reference to anger, rage, or violence) was the most frequently mentioned (60 occurrences). Notably, anger was reported more often than any of the symptoms included in the DSM diagnosis of major depressive disorder, with the exception of sadness.

Anxiety was added to cover symptoms such as worry, anxiety, and nervousness. Anxiety symptoms are commonly known to co-occur with depression (Sartorius, Ustun, Lecrubier, & Wittchen, 1996; Watson *et al.*, 1995) and are included in several prominent measures of depression (Hamilton, 1960). However, a goal of the parent study was to establish separate, mutually exclusive hierarchical structures for anxiety and depression in an attempt to differentiate between the conditions. As such, anxiety had been excluded from the depression hierarchical structure.

The final symptom-related conceptual categories captured references to paranoia, regretful rumination, substance use, alexithymia, avoidance, amotivation, and emotional pain. Though there was an *a priori* conceptual category for rumination, participants described the concept differently than common research or clinical definitions, which relate to the negative over-interpretation of symptoms and interpersonal slights (Nolen-Hoeksema & Morrow, 1991). Patients described intrusive thoughts of regret and self-blame about past mistakes that were conceptually distinct from the *a priori* conceptual categories (e.g., self-criticism, worthlessness, and guilt); we labelled these ‘regretful rumination’ (see Watkins, 2008). Although paranoia, alexithymia, and amotivation were infrequently endorsed, several participants described each of these symptoms as clearly associated with depression. However, their descriptions were more general than any symptom conceptual category in the *a priori* hierarchical structure. To appropriately categorize these experiences, we added conceptual categories for each. Lastly, we added conceptual categories for ‘substance use’ in order to capture references to alcohol or substance use in response to depression and ‘emotional pain’ in order to capture participants’ descriptions of non-physical but marked pain that was distinct from depressed, labile, or irritable mood.

Three additional conceptual categories captured contextual facets of depression. References to the death of a loved one, relative, or, on a few occasions, a pet, were coded ‘grief’. Usually, grief was mentioned as a cause of depression. Participants also repeatedly discussed methods they used to remediate their depression, which were coded as ‘coping’. Participants’ idiosyncratic descriptions of the causes of their depression were coded ‘causal attribution’ regardless of the evidence base for such assertions. Causal attributions ranged from comments regarding familial transmission of depression to weather as a cause of depression (see Table 5).

In addition to the aforementioned conceptual categories with specific content, a catch-all ‘other’ code was added to identify salient but infrequently mentioned experiences. Included were experiences of stigma associated with depression and idiosyncratic comments. After removing quotes assigned to an *a posteriori* conceptual category, quotes remaining in the ‘other’ code category typically did not pertain to the symptoms of depression and were idiosyncratic enough not to merit separate categories or additional codes.

Inter-rater reliability of coding

As stated above, a third coder reviewed the transcripts and independently applied codes. These codes were then compared using a kappa calculator developed by QDAP scientists (available at http://cat.ucsur.pitt.edu). Calculated across transcripts including codes assigned at least 10 times in the primary coding process, $\kappa = .56$.

Discussion

To our knowledge, the present work represents the first attempt to determine the degree to which individuals with personal experience with depression (whether of clinical or subclinical severity) spontaneously identify the same symptoms and constructs that researchers and clinicians use to describe, assess, and diagnose depression. Frank *et al.* (2007) conducted a similar focus group study with depressed individuals, but used a discussion guide based on specific diagnostic symptoms. In contrast, our probes were open-ended allowing participants to describe their symptoms in a more naturalistic way. Thus, we hoped to capture patient experiences of depression without biasing them towards symptoms that are considered diagnostically important.

We found that individuals with mild to severe depression do report the vast majority of symptoms that clinical researchers have identified as diagnostic indicators of depression and depressive symptom severity. Over 90% of the *a priori* hierarchical structure was generated by participants in response to open-ended probes, including cognitive, behavioural, social/interpersonal, somatic, and affective components of depression. In contrast, only three *a priori* conceptual categories were not mentioned by focus group participants, while nine concepts mentioned by participants were not included in our *a priori* codes. Of these, anger and anxiety were most frequently discussed (see Table 4) while the remaining *a posteriori* conceptual categories were mentioned 10 or fewer times. Interestingly, Frank *et al.* (2007) also identified anger and anxiety as key components of depression that emerged among their focus group participants. Our results (and those of Frank *et al.*, 2007) provide reassuring evidence that depression, as described by patients across the depressive spectrum, is generally well characterized by existing assessment tools and methods. Focus groups generally did not require the generation of new items for depression and supported the content validity of the original PROMIS conceptual framework and item pool.

In addition to confirming existing methods, our focus group findings highlight several promising avenues for future inquiry. One area is the centrality of strained interpersonal relationships in major depressive disorder. Of the *a priori* conceptual categories, we found that interpersonal concepts (loneliness, interpersonal alienation, interpersonal conflict, and social withdrawal and isolation) were the most commonly endorsed [175 unique occurrences out of 744 quotes (24%)] and were among the 10 most frequently used codes. Although there was a specific probe asking about the interpersonal impact of depression included in the focus group guide, interpersonal conflicts were spontaneously mentioned quite early in discussion. In 3 out of the 4 of the focus groups, the moderator omitted the specific interpersonal impact probe because the topic had already been thoroughly discussed. This speaks to the weight and importance that participants gave to the interpersonal consequences of depression. One possibility is that the interpersonal conflicts mentioned by participants, particularly in the depression group, are a function of personality disorders. Certainly, depression and personality disorders are often comorbid (Dunayevich *et al.*, 2000; Leibbrand, Hiller, & Fichter, 1999; O'Brien & Vincent, 2003; Starcevic, Bogojevic, Marinkovic, & Kelin, 1999; Verheul, 2001) and interpersonal difficulties have been used to screen for personality disorders (Pilkonis, Kim, Proietti, & Barkham, 1996; Scarpa *et al.*, 1999; Stern, Kim, Trull, Scarpa, & Pilkonis, 2000). However, there was no screening for or diagnosis of personality disorders completed as part of this study and this idea will need further research.

The centrality of interpersonal comments in our groups is consistent with a large body of research demonstrating the negative effects of depression on interpersonal relationships. There is theoretical and clinical support that points to negative interpersonal function as both a propagator and perpetuator of depression (see Joiner, 2000). Similarly, interpersonal stressors are often associated with the onset of depression in psychotherapy theory, providing inroads for treating depression. This can be seen in the interpersonal psychotherapy (IPT) model (Klerman, Weissman, Rounsaville, & Chevron, 1984) for depression, which has demonstrated effectiveness in the treatment of mild to moderate depression. IPT conceptualizes disturbed social relationships as both a possible cause and consequence of depression and seeks to remediate depression by rebuilding interpersonal strengths. Other approaches also focus on interpersonal function as a means of alleviating depressive symptoms. Our findings suggest that interpersonal consequences should be examined in conjunction with the assessment of major depressive disorder in order to fully capture a participant's experience of depression. Our findings also broadly support overlap between the World Health Organization's (2007) tripartite framework of physical, emotional, and social health and participants' conceptualizations of what it means to be a 'healthy' individual, and supports Joiner's (2000) focus on the importance of interpersonal function on the initiation and maintenance of depression.

Research in psychiatric nosology (Krueger, 1999) suggests that the 'structure of common mental disorders' (excluding psychosis) can be captured at a general (second-order) level by two dimensions of psychopathology: an internalizing dimension reflected in unipolar depression and anxiety disorders and an externalizing dimension reflected in antisocial behaviour, anger, aggression, hostility, alcohol, and substance abuse. Our focus group findings were consistent with epidemiological studies documenting the substantial co-occurrence of internalizing and externalizing problems (Verhurst & van der Ende, 1993). Specifically, we found evidence that anxiety is an integral component of patients' experience of depression, and that externalizing behaviours such as anger and substance use are also viewed as symptoms of depression. Further research is needed to clarify the direction and nature of the relationship between these co-occurring problems and patients' experience of depression.

Another area worthy of further research is the importance of anger in characterizing patients' experience of depression. The frequency with which anger was spontaneously reported highlights the importance of this construct in our focus groups, echoing the experiences of other depressed focus group participants (Frank *et al.*, 2007). The relationship between anger and depression is not a new concept. The traditional psychodynamic conceptualization of depression describes depression as 'anger turned inward' against the self (Blatt, 1998; Troisi & D'Argenio, 2004). Previous studies in medically and psychiatrically ill patients have documented a relationship between anger and depression, with some researchers identifying a subtype of depression characterized by irritability and anger attacks (Fava, 1998; Fava *et al.*, 1993). Further investigation of patient experiences with anger may help to clarify the relationship between depression and anger, and may contribute to the depth and breadth of depression assessment.

A final area for future research is the role of personal narratives in conceptualizing emotional health. In our focus groups, personal narratives about contextual facets of depression, such as grief and coping, occurred frequently, even though these topics were not solicited by the facilitators. When our participants discussed depression, they wanted to talk about not only which symptoms they experienced, but how their depression had come about and what they have done about it. While contextual factors do not necessarily inform standardized assessments of depression, they suggest that attention to patients' search for meaning about their symptoms represents an important aspect of treatment.

A limitation of this work is the relatively small sample size. However, it should be recognized that the aim of qualitative research is to capture the experience of representative members of the population of interest rather than to accurately estimate population scores, as is the goal of quantitative work. As such, there is much more emphasis on the quality of the data than on the quantity in focus group work. That said CES-D scores for both the depression groups and medical condition groups were consistent with the epidemiological literature on depression. In the current study, the mean CES-D score in the psychiatric group was 20.5 (*SD* = 11.99), which exceeds the clinical cut-off score of 16 on the CES-D. The mean for the medical condition group was 10.3 (*SD* = 9.1), reflecting more ‘mild’ symptoms of depression and supports our goal of inclusion of individuals across the dimensional spectrum of depressive symptoms.

Although there is high comorbidity between physical illness and depression, it is possible that medically and psychiatrically ill patients experience symptoms differently. For example, ‘poor energy’ may be interpreted differently by someone suffering from cardiovascular disease than to someone suffering with a psychiatric condition. However, moderator summaries indicated a fair degree of overlap of both psychiatric and medical conditions in all of our groups. Thus, a fair critique may be that our samples were not divergent enough to distinguish between medically related depression and psychiatrically related depression. Given the prevalence of psychiatric and medical comorbidity, it may be misleading to recommend that future groups be conducted with more ‘pure’ samples. Instead, it may be useful in future work to recruit a broader sample of individuals from multiple sites to ensure coverage of the full spectrum of depressive symptoms and possible variation among demographic and diagnostic categories, especially given that depressive symptoms are commonly experienced by individuals, particularly chronically medically ill individuals, even if they do not develop a clinically significant depression as a result.

Another potential limitation inherent in most focus group research is that analysis is based on what participants report and may not completely reflect all of their experiences. For this reason, the fact that three concepts in the *a priori* hierarchical structure were not mentioned should not be taken to mean that they lack content validity. Elicitation of specific symptoms may require the types of pointed questions included in assessment batteries and symptoms checklists. An alternate explanation is that participants do not connect specific symptoms to mood disorders, because they attribute the symptoms to other medical, physical, or behavioural issues. It is also possible that individuals may not mention particular experiences when asked about depression because they do not associate them with depression, do not have insight into certain experiences or do not view them as pathological.

In addition, we were slightly disappointed in the inter-rater reliability statistic that we achieved. While our score of .56 was close to the .60 we consider to be acceptable, it is objectively low. However, given the number of categories that we identified for coding and the relatively minimal training that was afforded to our coder, we feel that our reliability score provides evidence that the coding system is moderately reliable. It is likely that the system could be simplified or more intensively trained to achieve more consistent results.

These limitations notwithstanding, the present work provides strong evidence that the symptoms and syndrome that psychiatry and psychology have defined as depression converges with how individuals in our sample experienced depression and conceptualize the construct. It also lends credence to the hierarchical structure developed in the parent study, PROMIS. With few exceptions, individuals representing the range of depressive symptomatology spontaneously described depressive symptoms that overlap significantly with clinical concepts of what it is to be depressed. However, this work also suggests that important aspects of the experience of depression, such as anger and interpersonal difficulties, may not be as well represented in the clinical assessments. Furthermore, there was a clear need for our participants to ‘tell the story’ of their depression rather than limiting their discussion to their current symptom profiles. As clinical science moves more towards patient-focused outcomes and assessment these themes deserve further attention.

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Appendix

Sample of focus group questions

Experience and description of depression

(1) What words or phrases do you use to describe depression to family or friends in terms of symptoms or feelings?

(2) What would you like to tell your doctor or clinician about your experience with depression? By this we mean to ask if there is something about depression symptoms that your doctor may not know about, may under-appreciate, or may frankly ignore.

- Do you describe depression differently to loved ones than doctors?

(3) Describe what your depression has been like in the last 7 days or the last time you felt depressed?

(4) I noticed that some of you used language about how much of the time you were depressed (e.g., the number of days) and some used language describing how bad or severe the depression was. In your opinion, is one of these aspects of depression more informative?

Frequency probes:

- Out of 7 days, how many days in a given week do you feel depressed?
- What proportion of a given day?

Intensity/severity probes:

- In the last 7 days, what was your worst day of depression like?

Impact of depression

(5) What impact has depression had in your life?

(6) How does your depression affect your relationships with members of your family and your friends?

(7) Which depression symptoms *interfere* with your day-to-day activities?

Management of depression

(8) What helps you continue in recovery and decreases your risk of getting depressed again?

Table 1

Characteristics of depression by assessment method

	DSM-IV-TR major depressive episode	DSM-IV-TR dysthymia	BDI	BDI-II	HAM-D	CES-D	MADRS
Depressed mood	X	X	X	X			
Anhedonia	X		X	X	X	X	X
Increase in appetite, eating, weight	X	X		X	X		
Decrease in appetite, eating, weight	X	X	X	X	X	X	X
Insomnia	X	X	X	X	X	X	X
Hypersomnia	X	X		X	X		
Psychomotor retardation	X				X	X	
Psychomotor agitation	X			X	X		
Fatigue or loss of energy	X	X	X	X	X		
Inappropriate or excessive guilt, worthlessness, self-criticism, failure	X	X	X	X	X	X	X
Diminished ability to think or concentrate, indecisiveness	X	X	X	X	X	X	X
Suicidal thoughts or thoughts of death	X		X	X	X		X
Crying			X	X	X	X	
Difficulty getting started; slowness initiating activity			X		X	X	X
Irritability			X	X	X		
Anxiety; fearful					X	X	X
Interest in sex, sexual functioning			X	X	X		
Pessimism			X	X		X	
Hopelessness		X			X		
Hypochondriasis			X		X		
Lowered threshold for negative affect						X	
Loss of positive reactivity						X	
Diurnal variation					X		
Attractiveness			X				
Motivation					X		
Somatic complaints					X		
Interpersonal sensitivity						X	
Loneliness						X	

Note. BDI/BDI-II, Beck Depression Inventory (Beck, Steer, & Brown, 1996; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961); HAM-D, Hamilton Rating Scale for Depression (Hamilton, I960); CES-D, Center for Epidemiological Studies – Depression Scale (Radloff, 1977); MADRS, Montgomery–Asberg Depression Rating Scale (Montgomery & Åsberg, 1979).

Table 2

Demographics by diagnostic category

	Psychiatric sample (*N* = 13; *N* (%) or mean (*SD*))	**Medical sample (*N* = 16; *N* (%) or mean (*SD*))**	***t* or χ^2**
Women	4 (31%)	10 (63%)	2.89
Caucasian	6 (46%)	9 (56%)	0.29
African-American	5 (39%)	6 (38%)	0.00
Married/living together	3 (23%)	10 (63%)	4.50^{*}
Age	48.7 (10.5)	59.5 (9.8)	2.84^{*}
High school/GED	4 (31%)	2 (13%)	1.45
Some college/technical degree	7 (54%)	3 (23%)	3.91^{*}
College or more	2 (15%)	11 (69%)	8.26^{**}
Income less than $20,000/yr	10 (77%)	2 (13%)	12.27^{**}
Employment rate	3 (23%)	5 (31%)	0.24
CES-D	20.5 (12.4)	10.3 (10.2)	2.37^{*}

Note. CES-D, Center for Epidemiological Studies – Depression Scale (Radloff, 1977); GED, General Education Diploma;

[*] $p < .05$;

[**] $p < .005$.

Table 3

Distribution of codes across groups and transcripts for the PROMIS conceptual categories

PROMIS subdomain	PROMIS conceptual category	Psychiatric group	Medical group	Total number of quotes	Multiply coded quotes[a]
Mood				175	
	Sadness/depressed affect	*59*	*36*	*95*	*53*
	Lowered threshold for negative affect	*18*	*10*	*28*	18
	Crying	17	*4*	21	*2*
	Irritability	8	14	22	*9*
	Moodiness/emotional instability	3	5	8	4
	Poor mood (distinct from grief or loss)	0	0	0	0
	Loss of pleasure	0	2	2	1
	Loss of interest	9	2	11	7
	Loss of positive reactivity	3	3	6	2
Cognition				200	
	Problems in attention/concentration	2	4	6	4
	Problems in decision making/problem solving	12	7	19	*8*
	Memory problems	2	3	5	2
	Mental slowing	2	0	2	0
	Rumination (intrusive thoughts)	4	7	11	3
	Pessimism	2	2	4	2
	Self-criticism	9	2	11	6
	Worthlessness	7	7	14	9
	Thoughts of being physically unattractive	0	3	3	1
	Loneliness/decreased sense of closeness and support	*27*	*12*	*40*	29
	Interpersonal alienation and sensitivity	*41*	*22*	*63*	*36*
	Hopelessness	16	*7*	23	10
	Helplessness/loss of mastery and self-efficacy	*24*	9	*33*	18
	Guilt/sense of punishment	10	5	15	8
Behaviour				168	
	Decreased general activity	4	8	12	10
	Impaired functioning	*19*	*10*	*29*	16
	Need for increased physical effort	0	2	2	2

PROMIS subdomain	PROMIS conceptual category	Psychiatric group	Medical group	Total number of quotes	Multiply coded quotes[a]
	Fatigue	6	6	12	4
	Physical retardation	1	6	7	4
	Interpersonal conflict/impairment	*32*	*20*	*61*	*31*
	Social withdrawal/isolation	*28*	*31*	*59*	*28*
	Agitation	0	2	2	1
Somatic complaints				101	
	General sleep difficulties	11	6	17	7
	Excessive sleep	10	4	12	8
	Troubling dreams	0	0	0	0
	Changes in appetite	1	3	4	2
	Changes in eating behaviour	5	2	7	3
	Changes in weight	32	22	3	1
	Problems with gastrointestinal functioning	1	0	1	0
	Somatic arousal	0	0	0	0
	Increased pain	*22*	*23*	*45*	*27*
	Poor/perceived health/general somatic concerns	*16*	*19*	*35*	24
Suicidality				20	
	Thoughts that life is not worth living	3	3	6	3
	Thoughts of death or self-injury	3	11	14	*1*

Note. Italic text denotes 10 most frequently used conceptual categories; ‘a’ indicates that this and at least one other code was assigned to the same quote.

Table 4

Definitions and exemplar quotes for symptom-related *a posteriori* conceptual categories

Category	Definition	Exemplar quotes	Psychiatric group	Medical group	Total quotes	Number of focus groups	Multiply coded quotes[a]
Anger	Expressions of anger such as rage and fury, aggressive acts, hostile attitudes	'I can't tell you how many times I have broke this, and broke that, and punched my fist through a wall.' 'When [participant] talked about suicidal, you can also feel homicidal. Because I wanted to.'	35	25	60	4	34
Anxiety	References to worry and nervousness	'But a lot of anxiety. It's like waiting for the other shoe to fall.' 'High anxiety and you know, worry about the future.'	7	7	14	3	5
Paranoia	Persecutory fears; thoughts that one is being talking about or plotted against.	'I don't know the right word but I find it a lot in my daughter who has depression and she feels like everybody is out to get her.' 'I'm basically paranoid anyway and it does exacerbate it.'	0	3	3	2	0
Regretful rumination	Intrusive thoughts regarding past failures; an inability to move on from negative events	'She can't get it out and she can't let go.' 'If somebody says 'What's going on?' I can just say 'Well this is ruined…this I screwed up here, I screwed up there…I blew this…I blew that…'	7	3	10	4	6
Substance use	Alcohol, street drugs, prescription misuse	'A lot of people when they get depressed will either smoke a lot, I mean, drink…' 'Both times I got laid off, I remember going home and having a couple of beers with a male co-worker or one of my friends would come over.'	1	2	3	2	0
Alexithymia	Inability to describe or label emotions	'The inability to reach out – not being able to express feelings.' 'I wouldn't allow my feelings to…I wouldn't allow myself to feel.'	2	1	3	2	2
Avoidance	Withdrawing from activity in general distinguished from social withdrawal	'I just want to lay here and…pretend the real world don't exist. '…when I enter the secret life, I'm avoiding…its like, almost like a denial factor.'	4	0	4	1	2
Emotional pain	General description of non-physical pain	'That kind of feeling is not something that anyone would want. It's hurting you. It hurts so that you can't – it's like something inside knotting up.' '…there's a lot of pain that goes on in depression, not only for you but the people around you.'	4	4	8	2	3
Amotivation	Descriptions of low motivation distinct from decreased activity or impaired physical functioning	'Yeah, it's kind of like just 'whatever" 'Can't go from thinking to action.'	5	0	5	2	4

[a] Indicates that this and at least one other code was assigned to the same quote.

Table 5

Definitions and exemplar quotes for non-symptom *a posteriori* conceptual categories

Concept (definition)	Exemplar quotes	Psychiatric group	Medical group	Total quotes	Number of focus groups	Multiply coded quotes[a]
Coping (efforts to control or remediate depression through action or cognition)	'I would take off and go to … a store where there was a lot of light and a lot of visual stimulation, I would get better … so that's what I do now.' 'You are talking about ways of coping. Like he was saying, some form of denial or compartmentalization. In my case, medication helps me function.'	63	51	114	4	40
Grief (reference to a loved ones' death in relation to depression)	'I had a death in my family. Me and my uncle was real close and that really took me down.' 'This was when my wife died, my dog died, and when a horse I got … died. Those were the three most remember-able [depression] times.'	13	17	30	4	19
Causal attributions (any description of factors believed to cause depression or symptoms)	'Because depression runs in families, which means that it's genetic, which means part of the reason I'm depressed is because my father's depressed, and he took out his depression on me.' 'Many times it is related to barometric pressure'	28	23	51	4	25
Other[b] (a 'catch-all' category for depression related comments not better categorized elsewhere)	'What is the true meaning of being depressed? Well, I call it the 'pressers' – depressed, oppressed, and suppressed.' 'The older you get … you become kind of invisible or people don't pay attention or respect you as much.' 'Being damaged.' 'I felt lost.' 'I felt like I was just falling into a bottomless pit.'	101	43	144	4	69

[a] Indicates that this and at least one other code was assigned to the same quote.

[b] The 'other' code was intended as a catch-all conceptual category, reliability was not addressed through the consensus process.