“I Didn’t Know What Was Wrong:” How People With Undiagnosed Depression Recognize, Name and Explain Their Distress

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BACKGROUND: Diagnostic and treatment delay in depression are due to physician and patient factors. Patients vary in awareness of their depressive symptoms and ability to bring depression-related concerns to medical attention.

OBJECTIVE: To inform interventions to improve recognition and management of depression in primary care by understanding patients’ inner experiences prior to and during the process of seeking treatment.

DESIGN: Focus groups, analyzed qualitatively.

PARTICIPANTS: One hundred and sixteen adults (79% response) with personal or vicarious history of depression in Rochester NY, Austin TX and Sacramento CA. Neighborhood recruitment strategies achieved socio-demographic diversity.

APPROACH: Open-ended questions developed by a multidisciplinary team and refined in three pilot focus groups explored participants’ “lived experiences” of depression, depression-related beliefs, influences of significant others, and facilitators and barriers to care-seeking. Then, 12 focus groups stratified by gender and income were conducted, audio-recorded, and analyzed qualitatively using coding/editing methods.

MAIN RESULTS: Participants described three stages leading to engaging in care for depression — “knowing” (recognizing that something was wrong), “naming” (finding words to describe their distress) and “explaining” (seeking meaningful attributions). “Knowing” is influenced by patient personality and social attitudes. “Naming” is affected by incongruity between the personal experience of depression and its narrow clinical conceptualizations, colloquial use of the word depression, and stigma. “Explaining” is influenced by the media, socialization processes and social relations. Physical/medical explanations can appear to facilitate care-seeking, but may also have detrimental consequences. Other explanations (characterological, situational) are common, and can serve to either enhance or reduce blame of oneself or others.

CONCLUSIONS: To improve recognition of depression, primary care physicians should be alert to patients’ ill-defined distress and heterogeneous symptoms, help patients name their distress, and promote explanations that comport with patients’ lived experience, reduce blame and stigma, and facilitate care-seeking.

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When patients explicitly request help for depression, primary care physicians (PCPs) generally initiate guideline-concordant care, including medication, referral for psychotherapy or appropriate follow-up.[1] However, not all people request help for depressive symptoms — and physicians often do not recognize patients’ emotional distress[2–4] — which might explain why one-fourth of people with major depression are undiagnosed[5] and fewer than half receive treatment.[6,7]

A critical but poorly understood step in depression care involves symptom recognition and disclosure. Even people who desire treatment may be unwilling or unable to disclose their depressive symptoms to physicians.[8] Patient-level barriers to disclosure include lack of knowledge (about the symptoms or treatment), socio-cultural factors (e.g. stigmatization,[9–11] beliefs about help-seeking), psychological factors (e.g. difficulty articulating emotions), discomfort discussing personal issues,[12] and the belief that physicians are not interested in or not able to treat depression.[13]

Discordance between physician and patient beliefs may also hinder depression care.[14–20] When patients attribute depressive symptoms to problems of living or physical illness,[14–16,21,22] physicians are more likely to overlook depression and pursue situational explanations or organic disease.[18,19] Unwillingness

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to seek care may result from discordance between patients' treatment preferences (generally, psychosocial interventions) and their expectations about what their physicians will recommend (generally, medications).[20]

To gain a deeper understanding of how people recognize their own depressive symptoms and bring them to the attention of their PCPs, we used focus groups to explore cognitive, relationship, and communication factors that affected recognition and disclosure of depressive symptoms.

METHODS

Focus groups were conducted with a diverse sample of people with personal and vicarious experience with depression; results from these groups informed the design of targeted and tailored media interventions to encourage depression care-seeking in primary care.

Study Sites & Participants

The institutional review boards at the three study sites (Rochester, New York; Austin, Texas; and Sacramento, California) approved the protocol. We purposively sampled participants to achieve maximum variation and representativeness by income, gender, and racial/ethnic background. In addition to on-line postings, we sent postcards, and posted flyers in public venues in Zip codes that reported median incomes closest to the 50th (middle-income) and 15th (low-income) percentiles.

Study participants were English-speaking men and women, aged 25–64, who reported a personal history of depression or experience with a close friend or relative with depression. Each participant received $35.

Data Collection

The team developed an initial set of guiding questions, based on theories of illness cognition,[14–16,23–26] and behavior change (e.g. transtheoretical model, social cognitive theory),[27–30] and research on depression care-seeking.[111] These approaches propose that people are most likely to seek treatment if they are well-informed and psychologically minded, experience typical symptoms of depression and little stigma, and have confidence in the effectiveness of treatment, few concerns about side effects, adequate social support, and high self-efficacy. Open-ended questions prompted participants to disclose their "lived experiences" of depression, depression-related knowledge and beliefs, and facilitators and barriers to care-seeking. The questions had a pragmatic goal — to help design media interventions for those in pre-contemplative and contemplative stages of care-seeking starting with the initial experience of symptoms continuing through treatment.

Before each focus group, participants provided informed consent, and completed a questionnaire. Groups lasted 75–110 minutes, and were facilitated by 1–2 study investigators. A project coordinator took notes.

Based on pilot focus groups (balanced for gender and income) conducted at each site, we expanded our guiding questions to explore two areas: the time between the appearance of depressive symptoms and the first realization that something might be wrong, and the interactions among people with depressive symptoms, their close social contacts, and the health care system that influenced care-seeking (see Appendix).[31,32] Using the revised guiding questions, we conducted four additional focus groups per site, stratified by gender and income level ("low", "middle"), in early 2008.

Data Analysis

Groups were digitally recorded, then transcribed. First, the entire multidisciplinary study team identified broad emergent coding categories based on iterative line-by-line review of 15 focus group transcripts. The codes were grouped into larger categories by consensus during regular meetings. Then, the primary coding team (DAP & CSC) reviewed the transcripts for accuracy while listening to the recordings and systematically coded all 15 transcripts using EthnoNotes software; they selected numerous illustrative quotes and identified each quote according to city, gender, and income group.

In the second phase, the data analysis team (RME, PRD, PB, JDB) refined codes pertaining to cognitive and communicative processes that hindered or enabled discussion of depression-related symptoms. They rechecked the transcripts, reviewed the codes and coded transcripts, refined definitions of the

Table 1. An Empirical Taxonomy of Patient Factors Influencing Depression Help-Seeking in Primary Care

Major category	Subcategory	Problem statement
Knowing	Not knowing	Lack of awareness that one's experience constitutes a problem
	Becoming aware	Situations or factors that led to awareness that something might be wrong
Naming	Social influences	Facilitators and barriers to awareness
	The lived experience	Participants' actual experiences of depressive symptoms, including perceptual distortions, metaphors of constriction, and social inhibition
Finding meaningful explanations	Problems with the word "depression"	Colloquial, personal and clinical understandings of the word depression.
	The value of naming	Effects of naming on care-seeking and self-image
	Formal assessment	The value and limitations of depression screening instruments
	Physical explanations	Depression is seen as a medical illness, requiring treatment
	Characterological explanations	Depression is seen as intrinsic to personality
	Situational explanations	Depression is seen as a response to current or past events

Table 2. Demographic Characteristics of Participants

	Participants (n = 116)	
	No.	**%**
Respondent type		
Personal Experience	56	48
Family member or friend	14	12
Both personal and family/friend	46	40
Sex		
Male	51	44
Female	65	56
Age, years		
25–45	54	47
46–64	61	53
Race/Ethnicity		
White	70	60
African-American/Black	19	16
Hispanic	16	14
Other	11	10
Educational Attainment		
Some high school	5	4
High school graduate/GED	18	15
Technical school/some college	38	33
College graduate	54	47
Annual household income (US Dollars)		
>80,000	13	11
50,001–80,000	15	13
30,001–50,000	23	20
20,001–30,000	14	12
<=20,000	50	43
Regularly practice religion/participate in religious community	54	47
In general, would you say your health is...?[a]		
Excellent	12	10
Very good or good	76	65
Fair or poor	28	24
Do you have any kind of health coverage...?		
No	23	20
Yes	90	78
Do not know/not sure	3	2
Was there a time in the past 12 months you needed to see a doctor but could not do so because of costs?		
No	73	63
Yes	42	36
Do not know/not sure	1	1
Is there a particular person or place that you usually go to when you are sick or need advice about your health?		
No	16	14
Yes	100	86
During the past 12 months, did you think you needed help for emotional or mental health issues, such as feeling sad, anxious or nervous?		
No	24	20
Yes	92	80
During the past 12 months, were you treated for emotional or mental health issues?		
No	43	37
Yes	72	62
Have you ever had treatment for depression?		
No	14	12
Yes (all treatments)	101	87
Yes, with medications	90	76
Yes, with counseling	98	84
How beneficial was the treatment you received?		
Not at all beneficial	3	3
Somewhat beneficial	35	30
Beneficial	35	30
Not applicable	41	35
Do you know of any close friends or family members who were treated for emotional or mental health issues over the past 12 months?		
No	35	30
Yes	79	68
How beneficial was the treatment they received?		
Not at all beneficial	7	6
Somewhat beneficial	40	34
Beneficial	26	22
Not applicable	35	30
I would not want my employer to know I was getting professional help for an emotional problem.		
Strongly agree or agree	74	64
Unsure	17	15
Disagree or strongly disagree	24	21
I would be embarrassed if my friends knew I was getting professional help for an emotional problem.		
Strongly agree or agree	28	24
Unsure	29	25
Disagree or strongly disagree	59	50
If I had depression, my family would be disappointed with me.		
Strongly agree or agree	24	21
Unsure	22	19
Disagree or strongly disagree	69	60

[a] *Some percentages do not add up to 100% due to rounding or non-response. Further information available from the authors*

codes, defined sub-codes, searched for recurrent themes, generated hypotheses, and extracted representative quotes from the initial set that exemplified each sub-code. The team organized relevant codes and transcript segments into three themes (Table 1) and explored theoretical links among the codes and themes. Disconfirming data were used to modify themes and refine hypotheses. Co-investigators not involved in the initial phases of the analysis audited the results for consistency, clarity, and comprehensiveness (MPF, ABR, RLK). Data relating to gender, social and patient-physician relationship issues are reported elsewhere.[33,34]

RESULTS

Study Participants

One hundred eighty-three people responded to our recruitment efforts; 37 were unavailable or ineligible due to age or income. Among the 146 remaining volunteers, we were able to accommodate 116 (79%) participants into one of 15 scheduled focus groups (Table 2).

Naming, Knowing and Explaining

Participants described three linked themes: their inner experiences of depression as they first recognized that something was wrong ("knowing"), sought to put a name on their distress ("naming") and tried to make sense of their experiences ("explaining") (Table 1).

Knowing

We first examined how people became aware that their experience of "depression" might represent something abnormal or undesirable (Text Box 1)

Text Box 1. Knowing

Not knowing	
Inability to see what others perceive	*"You don't even realize your depressed, but … your demeanor, everything that everybody else sees, I don't know, it's [stammers] totally different than what you're feeling,…and you don't even realize it." [LI Female]*
Extraverted personality	*"I don't know why all of a sudden this person with personality and gregarious and friends all of a sudden doesn't want to deal with it, telling people I don't want to go anyplace and they're going, "What's wrong with you?" And then family saying, "Snap out of it." You know, snap out of what? I don't even know what I'm in." (laughter) [Pilot Male]*
Depressive personality	*"For me, depression covered my whole life. I didn't even know it, because I've had it all my life. I don't know, I can't even trace it to roles in the family, and stuff that went on, I just figured that I had it, and was basically born with it." [LI Female]*
Becoming Aware	
Growing awareness	*[..it reached] "a level where you just know… you gotta do something -- you get sick of it." [LI Male]*
Emotional and behavioral changes	*"Everything was just going crazy and I couldn't get a grip. And I've always had a grip. And I've always been in control…. just not wanting to go outside and not wanting to talk to people" [Pilot Male]*
Negative thoughts	*"I could tell something was wrong because... all I had was negative thoughts - negative thoughts about my son… I--I was imagining all the worst things that could happen to him…" [MI Female].*
Physical symptom	*"Originally, I think I thought it was just a physical ailment but I was continually losing weight like a lot of weight. It got a little scary …" [MI Female]*
Vague sense that something was different	*"I clearly--I didn't know what, um, was wrong with me. I just knew something was different, so I couldn't even identify what it was. …So I was really lost, so I couldn't gather the words to even ask for help." [Pilot Female]*
Sentinel events	*"I just had out of control crying. And I was really, totally, completely out of control. And you know, it was such a crash, because before that I thought that I was like Spock, you know, completely sound minded…. 100% rational. And you know, when I came down, I came down real big. And you know, after struggling with that for like three, four months, finally I realized that I really needed help." [LI Male]*
Social factors	
Advice from another person	*"I don't think I recognized when I was depressed quite honestly…it was people telling me to, you, know, maybe you ought to consider that, you, know, you're in a state of depression and you might want to seek help from a counselor." [Pilot Male]*
Lack of acknowledgement and acceptance	*"Nobody talked about depression, um, but I tell my friends I'm going to get my motorcycle and drive it through a McDonald's window… it seems like it would have been pretty obvious…" [Pilot Male]*
Unwillingness to talk about depression	*"I do remember at age 14 hiding my crying and being depressed. I didn't know what it was. I—I grew up in a family of secrets: there was alcoholism that was a secret, there was incest that was a secret, and I just knew this was one more thing to keep secret." [Pilot Female]*
Mixed messages	*"They said that I was okay and that I would just have to get over it." [Pilot Female]*
Social comparison	*"A girlfriend at the time… was going to therapy three sessions…a week. And she was dealing with some real serious issues. Far more serious than what I was dealing with…And here I am, going through some little stuff." [Pilot Male]*

LI = member of the low-income mens' or womens' focus group; MI = member of the mid-income mens' or womens' focus group; "Pilot" = member of the pilot mixed gender focus group, income unknown

Not knowing. Many participants reported not knowing that something was wrong — sometimes for years. One participant did not seek treatment because they "didn't know there was anything wrong with me…" Another was "totally unaware" but, in retrospect could "pinpoint times even as a teenager that I obviously isolated myself." Some were equally unaware, despite having had prior treatment for depression.

Several participants described how personality can influence knowing. Some who described themselves as "always dark," "introspective", and "always in a bad mood" had been so acclimated to being "gloomy" that it was difficult for them to appreciate their descent into depression. In contrast, self-described extraverts, unaccustomed to introspection or negative emotions, were not attuned to the nuances of their moods. They had difficulty reconciling a self-image as an "outgoing likeable person" with the experience of depression. Traits also made it more difficult for participants' family members and friends to know they were depressed.

Becoming aware. A surprisingly wide range of emotional and behavioral changes, physical symptoms, and perceptual distortions cued participants that something was wrong. Some described a "growing awareness;" others described sentinel events — hospitalization for substance abuse or "feeling totally out of control." Many reported delays in seeking care, especially lower-income men. By normalizing their symptoms as "everyday life problems that many other people are going through" they delayed until their distress was extreme before seeking help.

Social influences. Family members, friends or health professionals "pushed" some participants towards knowing. Others reported the opposite –friends and family seemed unable to notice or discuss depression, even suicidal statements. One man commented, "…you're not looking for help and … there are people around that aren't recognizing it either." Spending time with someone in the midst of depression did not facilitate recognition of depression in oneself; some individuals perceived their own distress as categorically distinct from the clinical depression of their friends or loved ones.

Naming

Once having recognized that something was “not right,” participants described difficulty naming their distress. Below, we discuss four aspects of naming (Text Box 2).

Text Box 2. Naming

Growing awareness	*“…looking through a foggy window and you just cant get the haze off,” [MI Female]* *“…casting a shadow on… every single thing in my life.” [LI Female]*
Metaphors, mainly of constriction	*“…depression attacks me…like a cloud or blanket that just lays over me. It’s like something oppressing me…Not …. like…something I’m feeling.” [Pilot Female]* *“Like a train going down the track, and you’re trying to get someplace but there’s friction on the track.” [MI Female]* *“…either not wanting to see your way through the tunnel or not thinking there is a way out of the tunnel [MI Female].”* *“…being in the bottom of a very big tank and the top is way up there and you can’t see it. All you see is the tank, you know, and that feeling of, of no alternatives, of darkness.” [MI Male]*
Social inhibition	*“If [the conversation] gets too happy, toning it down a bit, like, adding some sarcastic comment or something because people are too happy.” [MI female]*
Problems with the word depression	*“…if there’s only one depression why are some people on Zoloft, some people are on Prozac, some people are on Cymbalta. Obviously depression is just a general label I would think because I mean, you wouldn’t be treating the same thing.” [MI Female]* *“[Depression] is similar to the word ‘love’: I love pizza. I love my dog. I love money. I love my husband.” [MI Female]*
	“My brother had cancer and he was not his cancer… When you talk about depression, [saying], “Oh, she’s depressed,” to me that’s like [saying]… my brother he’s ***not*** *cancer, you know, he* ***had*** *cancer. We* ***have*** *the depression illness.” [MI Female]*
Using questionnaires to assess depression symptoms	*“I didn’t really recognize and put a term to it until … there was an inventory that you could sit down and …score a number and attach a number to. And even though that number—I… recognized is somewhat subjective, I could still, with some level of confidence say, “Yes. That’s true. Yes. That’s true. Yes. That’s true.” [MI Male]* *”… everybody… wakes up too early sometimes or… goes to bed and sleeps too long…so … how does this make me different than the average person? …The surveys I’ve seen …haven’t …convinced me that, ‘Oh, I’ve got something unique. I’ve got depression.’” [MI Female]*

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The lived experience. Women, especially mid-income women, described more aspects of the depression experience than men. Participants’ experiences included symptoms (e.g., mood, interest, appetite, sleep, energy, slowing) typically considered to be diagnostic criteria for depression,[35] as well as other domains: perceptual distortion, metaphors of constriction and social inhibition. Commonly, participants felt as if there were actually “haze,” “fog” or “shadows” that affected their ability to see clearly. They used metaphors, most commonly of enclosed spaces with no way out. One woman suggested that depression was “the monster” that “you can’t see” but “all of a sudden they put a name on it,” allowing it to “be fixed with …a pill or something.” Social inhibition was manifested by not answering the phone, not going out, not shaving, or making sarcastic or negative comments in social situations. Because patients did not name these experiences as “depression”, “[…asking], ‘Have you ever had depression?,’ probably isn’t the best [question] to use, because if you aren’t recognizing it at this point, you can say, ‘no.’”

Clinical and colloquial use of word “depression”. Participants commented that the words “depressing,” “depressed”, and “depression,” are used colloquially (“So depressing that they didn’t win”), as a personality characteristic (“He’s always down and depressed”) and as a clinical name for an illness (“I am being treated for depression”). In addition, some participants’ narrow concept of depression interfered with recognition and acceptance of the diagnosis. In one focus group, mid-income women expressed confusion about why only one word, “depression,” was used to describe such diverse experiences, time courses, and treated disorders.

The value of naming. Despite the problems with the word “depression”, participants did not dispute the value of naming their distress. Because they saw depression as “beyond sad,” participants searched for qualifiers to capture the differences between depression and ordinary sadness– it “spirals down,” “lasts longer,” and is “ “deeper,” “more painful,” and “irrational”. One low-income woman reflected a common perspective that “depression is more of a medical thing, where sadness could be, maybe, from tragedy.” Depression often involved “lacking control” over one’s own thinking.

Participants remarked that they often avoided the word “depression” with friends, family, and employers – to avoid misunderstanding, stigmatization or over-burdening others. One low-income woman said, “…if I tell my family….I would say that I’m sad or I’m tired. I don’t say I’m depressed.” Many participants reported that a diagnosis of “depression” had a paradoxical result on their recovery. On the one hand, naming distress as “depression” led to improved access to medical treatment. Conversely, participants feared losing the very social support that could help them overcome depression — friends and family might avoid or blame them, and they might experience employment discrimination.

Questionnaires. Completing a depression questionnaire played an important legitimizing and exculpating role for several participants; it helped attach words to experience, convince them of the gravity of the situation, that it was “real….not just in (their) head(s)”. One mid-income male participant noted that he used to “associate” depression with “crying, sadness…

inability to kind of cope and…and get on with life” but that “didn’t describe (his) situation at all.” However, once he “sat down and …faced that questionnaire,” he realized that he was suffering from depression, despite his ability to “bring home a paycheck.” While men generally reported positive reactions to depression screening questionnaires, several women objected to the checklist quality of the questionnaires preferring a more personal approach.

Explaining

Finding meaningful causal explanations for their distress allowed participants to organize their experience and engage with health care professionals. Three types of explanations were identified: *physical, characterological, and situational* (Text Box 3). Most favored a single explanation, but some *combined* two or more types of explanations into a coherent narrative; more often, the link between the two (or more) explanations was not made. A few participants commented that they could find no meaningful explanation for their distress.

Text Box 3. Physical, Characterological and Situational Explanations for Depression

Physical explanations	*“Once you realize what exactly is going on inside of you, chemicals in your body and knowing that you can correct it, it’s a big relief.”[Pilot Male]* *“It’s a real physical thing going on and that it’s not just your will. It’s not just your attitude.”[MI Female]* *“My mother always said I’m going to be mentally ill because my mother was mentally ill” [MI Female]* *“I think when I see my son…there’s sometimes a little guilt associated with it…Young people [may] think ‘I don’t want to pass depression onto my kids... Maybe I shouldn’t have children…’” [LI Male]*
Characterological explanations	*“It was always so shameful… I thought it was…a character flaw. I didn’t know it was…physical--I was fighting my own brain…I didn’t know that. My brother died from cancer…That was…not a shameful thing…His body had cancer. My body happens to have depression. “ [MI Female]* *“…this depression thing was like the one thing that I didn’t have control over. Like, you know, babies can put themselves in a good mood, why couldn’t I? [MI Female]*
Situational explanations	*“…when you’re a kid…some families…don’t give you that nurturing time…somewhere along the way, [you] get lost and slip through the cracks… [leading to]… emptiness* [and you] *grow up to be this kind of person.” [Pilot Female]* *.”.something that…doesn’t fit the mold of being a good catholic such as being gay ….that gives [your family] reason to …create distance between you [and them] and that drives depression” [Pilot Male]* *“We’re taught not to be angry, and so you pack down the anger…and you just…take it in, take it in, and it just builds up, builds up, until…you’re depressed…” [LI Female]*
Combined explanations	*“I think I have genetics, but I think when I look back I think a lot of mine was, like, post traumatic stress induced— “ [MI Female]* *“Um, you start down the road of depression and, you know, bad thoughts, and it changes the chemistry. And so you get some medicines that help change it back, but you have to change the thinking.” [MI Male]*
Unable to identify an explanation	*“So I’d think….why do I feel this way? I have a decent job. I have a loving family. I have no illness.” [MI Male]*

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Physical explanations. Physical explanations — depression as a “medical condition,” “disease,” or “illness” — were welcomed by those who initially had explanations that involved self-blame. Often, physical explanations were offered by health care professionals, family members, celebrities or advertisements, which the patient then adopted. Participants typically referred to “chemicals” being “imbalanced” or “blocked.” Others attributed depression to menopause, or lack of sexual vigor (“my mojo is gone…”). Whereas “chemical imbalance” typically reduced stigma and blame, genetic attributions left a more complex wake, which involved blame ascribed to a prior generation and to themselves for their role in transmission to future generations.

Characterological explanations. Participants who felt that depression was “just part of me” or “I’ve been depressed since I was born” had more difficulty recognizing that they had a condition that needed treatment. They viewed their propensity to depression as a personal weakness, lower self-worth and a “shameful” lack of control. Participants who used the term “depressed” to describe a personality characteristic (rather than a treatable clinical condition) seemed less likely to seek care.

Situational explanations. When depression was also viewed as a result of current stressors (e.g., accidents, deaths, family conflict) and past events, participants felt that social factors were to blame for their distress and that changing the social environment would be necessary to alleviate depressive symptoms. Often “several things… jumped on you at one time;” many were woven into life’s daily fabric — “wear[ing] yourself out taking care of everybody else” and “not being able to let go of a relationship.” One participant noted that “people or situations…have a negative effect on you” and one would be well-advised “to stay away from [these] influences.” Participants also referred to childhood trauma and neglect (e.g., insufficient “lap time”), and parental divorce, substance abuse and mental illness. One man attributed depression to conflicts between his emerging sexual orientation and his family’s religious beliefs. Others noted secretiveness of their early emotional environment leading to self-silencing and internalizing their distress.

DISCUSSION

Our demographically and geographically diverse participants described three themes relevant to presenting depression-related symptoms to primary care physicians and engaging in care — "knowing," "naming", and "explaining." Our findings also suggest ways in which theories of diagnostic delay, illness cognition and health behavior change can inform interventions to improve depression care.[25,28,29,36]

Whereas research on diagnostic and treatment delay tends to emphasize physician factors (such as misattribution), our findings underscore the importance of patient-related delay.[25,36] For example, "not-knowing" can be seen as a type of appraisal delay. While "knowing" can promote care-seeking, sometimes patients come to "know" that something is awry during discussions with physicians about experiences that initially seem unrelated to depression, such as pain, fatigue, and a vague sense of "just not feeling right."

"Naming" refers to how people find words to describe their distress. "Naming" is often a precondition for the contemplation phase of behavior change; conversely, not naming one's distress as depression can contribute to "illness delay" — the temporal gap between deciding one is ill and seeking care. Many participants had difficulty naming their distress as depression because their experiences did not comport with their "common-sense" models of depression.[24] Nor were many of these experiences likely to have been considered depression symptoms by their physicians, who held different but narrow models that did not encompass the protean ways in which people experience depression. Expanding the public's concept of depression and physicians' ability to accommodate diverse experiences of depression may facilitate dialogues between patients and physicians and lead to earlier recognition.

The word "depression"– with its colloquial connotations and associations with immutable personality characteristics — presented multiple subtle issues. Participants found it less stigmatizing to say "I *have* depression" rather than "I am depressed," just as men might refer to *having* erectile dysfunction rather than *being* impotent. Based on prior reports, we thought that older patients, Blacks, Latinos, and Asians would have more difficulty naming their distress as "depression;"[37] we found that naming was problematic for everyone. Standardized depression screening tools,[38] helped many "name" their depression, but some women found them unhelpful.

Meaningful explanations, our third theme, were strongly influenced by social relationships patients have with health care professionals, friend and family, and by the media.[31] Arriving at an understanding of depression that comports with personal illness beliefs, exculpates ("not my fault'), instills hope ("treatment can work"), and empowers ("I can do it"] can promote movement from contemplation to action.[23–25,27–30] But, not all explanations propel people along the path to care. The most motivating and destigmatizing explanations represented a balance between physical, characterological and situational attributions. While most participants ultimately preferred physical (e.g. chemical imbalance) to characterological attributions, they often recognized that "chemical imbalances" neglected the uniquely personal aspects of the depression experience — and devalued behavioral or psychosocial treatment options. Furthermore, participants felt that personality traits and social forces were important to consider in promoting recognition of depression. However, holding predominantly situational attributions, while defusing self-blame, often resulted in beliefs that changes in the social environment — not medical care — were necessary to improve their mood, functioning, and self-concept.

Our observations are relevant to both patient-physician communication and the development of clinical, public health, and media interventions to improve depression care. First, depression-related information should emphasize the diverse ways in which people experience depression. Second, common difficulties with the word "depression" should be addressed. Third, explanations for emotional distress should take into account individual vulnerability — due to personality, situational, social, and genetic factors — while being careful to avoid blame and emphasizing responsiveness to treatment. Fourth, physicians should not rely on symptom checklists exclusively to detect depression. Finally, discussions of depression-related concerns with PCPs should not require that the patient endorse a self-diagnosis of depression.

Several limitations should be noted. First, self-selected volunteers from urban areas — with prior psychotherapy and pharmacotherapy — present different views than undiagnosed people with depression presenting in primary care. Second, depression diagnoses were by self-report. Finally, focus groups cannot explore themes in as much depth as individual interviews and can foster collective thinking which reinforces some themes and avoids others.

CONCLUSIONS

A framework that considers the role of health systems, illness cognition, behavior change, and social influences can advance our understanding of how people come to know, name, and explain their depressive symptoms and seek care. To bring depressive symptoms to the attention of physicians, people must first become aware that their ill-defined, heterogeneous and (often) longstanding distress is not normal and warrants attention. While labeling their experience as "depression" is often helpful, in order to seek care, people also need meaningful explanations for their distress that comport with their lived experience, reduce blame, stigma, and shame and provide hope that interventions will help. Physicians, families, friends, and the media can prompt people who have depressive symptoms to seek care by adopting a multi-faceted understanding of the experience of depression from the patient's perspective — and helping them find the words to bring their experiences and concerns to the attention of physician. In that way, a shared vision of the cause and treatment of depression can facilitate follow-through with a mutually-endorsed plan.

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APPENDIX — FOCUS GROUP GUIDING QUESTIONS

Clinical stage	Guiding questions
Appearance of depressive symptoms	If you thought you were depressed, whom would you tell?
	When you think about depression, what comes to mind?
Perceived need for action	Some people might seek help for depression; other people might decide not to seek help. How would you (or someone else) know that you needed help for depression?
	What kinds of things do you think should be said to someone who was depressed and who you thought needed treatment?
Care-seeking	If you were feeling depressed, where would you go to seek care/get help?
	Where would you go to get help if you thought your family member or close friend was depressed? (If responses for self and other differ, probe for why)
	What kinds of things might make it difficult for people to get help/seek care?
	Tell me your thoughts about the average person's ability or willingness to seek care for depression from the doctor who cares for their general health concerns. We will call this doctor the "main doctor." How might these expectations impact your willingness to seek care?
Treatment	Let's talk now about specific kinds of care for depression
	Please tell me how you feel about the usefulness of antidepressant medication for the treatment of depression
	Please tell me how you feel about the usefulness of counseling or psychotherapy for the treatment of depression
Other issues	Tell us about other issues that may be important to identifying and managing depression. Are there certain beliefs, values, or personal characteristics that are important?
	Tell me how your own beliefs, values, or personal characteristics might influence your interaction(s) with your main doctor. Are there things in addition to your own beliefs, values, or personal characteristics that make a difference in how your doctor should help you with depression?