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Surviving Depression: Clinical Qualitative Analysis of Long-Term Survival for Ethnically Diverse, Depressed Patients

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Abstract

Depression is persistent and recurrent across ethnic groups. Few narrative analyses of long-term outcomes for ethnically diverse adults with depression exist. We combined 9 years of quantitative data, qualitative interviews at 10 years, clinician ratings of outcomes, and a community discussion group with the objective of describing long-term recovery and survival of diverse primary care patients following an episode of depression. Nearly half of participants were found to be depressed at some time over a ten-year period and a majority of cases across ethnic groups were judged to need further treatment. The ethnically diverse community members that analyzed the transcripts emphasized assets that participants showed in surviving multiple life stresses. Different gender and ethnic/racial groups had different characteristics of engaging in care, with Latino women in particular raising concerns about care engagement, coping with stress, and long-term outcomes.

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Depression; primary care; racial and ethnic disparities

Introduction

Depressive symptoms and disorders can persist and recur, and affect ability to function and quality of life over many years (Hirschfeld et al., 2000; Kessler et al., 1994; Spitzer et al., 1995; Wells and Sherbourne, 1999). Effective treatments for depression exist, but many individuals with depression do not receive treatment or have their only care in primary care where their depression may not be recognized by their providers given other competing demands for providers' attention or the provider fails to deliver quality care (Kessler et al., 1999; Rost et al., 2000).

Substantial ethnic and racial disparities in quality of care and outcomes for depression exist, including in primary care (Lopez et al., 2006; U.S.D.H.H.S., 2001). Primary care-based quality improvement interventions for depression are effective for improving the quality of this care (U.S.D.H.H.S., 2001) and its outcomes for majority White and ethnic minority populations (Murray and Lopez, 1996). Quality improvement interventions may decrease ethnic and racial disparities in outcomes of depression care (Miranda et al., 2003b; Wells et al., 2004b; Wells et al., 2007b). Nevertheless, such programs have not been routinely available in under-resourced communities, and minorities remain at risk for lower rates of engagement and retention in care for depression and, thus, are at risk for poor long-term outcomes. Relatively few studies have examined long-term outcomes of depression in ethnically diverse, primary care populations including after participation in practices trained in quality improvement programs for depression.

Given national policy trends that prioritize medical homes with integrated behavioral care, and expanded benefits for mental health care for low income populations (S.A.M.H.S.A.-H.R.S.A., 2012), understanding factors that affect long-term outcomes of depression care in this population is both timely and important for developing more effective interventions. Long-term outcomes may be mediated by ongoing symptoms and their impact on functioning and well-being, exposure over time to multiple life stressors, and changes with age in coping resources, such as social or financial supports (Djernes, 2006). Although narratives about depression have been reported (Charmaz, 1991; Clark, 2008; Karp, 1994; Westerbeek and Mutsaers, 2008; Wolpert, 2001), further information about patients' experience of long-term outcomes may be useful, for example, to identify coping strengths that patients, providers or families could build on to support improved outcomes over time, clarify barriers to care and strategies to support ongoing engagement in care, or identify feasible additional interventions to help decrease consequences of depression over time. Recent studies suggest that long-term symptoms may be managed by continuation of medication or evidence-based psychotherapy, but many depressed individuals who have received initial care, especially ethnic minorities, may not continue in care, suggesting a need for feasible long-term engagement strategies (Hollon et al., 2005).

Obtaining multiple stakeholder perspectives on long-term outcomes may be particularly valuable, as patients' perspectives may be affected by accommodation to symptoms or life circumstances, while clinicians may have their own perspective based on training or experience, but may not be aware of patients' long-term experience, especially for groups not regularly engaged in care. Community members who are aware of the local context of under-resourced communities may provide valuable perspectives on the meaning of patients' experiences from those communities.

To our knowledge, no study has analyzed depressed patient narratives of their experience years after an initial primary care encounter in practices participating in some form of depression quality improvement, and especially within the context of identifying the perspectives on those outcomes of diverse stakeholders (patients, clinician reviewers, community reviewers). In this study, we present survey data on depression outcomes sequentially over nine years after initial identification of high risk for depressive disorder among adults in primary care practices who participated in the Partners in Care quality improvement study (Bromley et al., 2016; Wells et al., 2004b). At ten-year follow-up, we oversampled Latinos and African Americans and a matched White sample and conducted qualitative, semi-structured interviews. We include clinician ratings of data from these interviews.

Our goal is to generate hypotheses for further study by describing the range of residual symptoms that people experience ten years after identification and their coping strategies for symptoms and life events; and to use expert clinician ratings to describe their clinical status, gaps in the appropriateness of their care, and needed augmentation to current care. The specific questions underlying this paper are: 1) What depressive symptoms do people describe ten years after being identified as depressed in primary care? 2) What coping strategies do people use to ward off stressful events or to deal with those that occur, and how do those strategies differ across gender and ethnic groups? 3) What therapeutic or social support strategies do people use to improve long-term recovery from depression in diverse populations? 4) To what degree are they engaged in appropriate treatment, and which additional services, supports, or treatments would experienced clinician raters recommend? Our focus is on integrating perspectives of diverse stakeholders to better understand the experience of patients and inform potential intervention strategies and future research.

Methods

The data are from the parent Partners in Care (PIC) study (Jaycox et al., 2003; Miranda et al., 2003a; Miranda et al., 2004; Schoenbaum et al., 2004; Schoenbaum et al., 2005; Schoenbaum et al., 2001; Sherbourne et al., 2001; Unützer et al., 2001; Wells et al., 2004a; Wells, 1999; Wells et al., 2007a; Wells et al., 2000; Wells et al., 2007b; Wells et al., 2008) and a continuation study conducted at ten-year follow-up. See Figure 1 for a graphic representation of the entire study. PIC was a primary care, practice-level, randomized trial of quality improvement interventions based on the collaborative care model of chronic disease management applied to depression, versus enhanced usual care that was fielded in Los Angeles, California; San Antonio, Texas; San Luis Valley, Colorado; and Columbia, Maryland. The study included 54 publicly and privately managed primary care practices.

Patients were identified through visit-based screening by study staff of consecutive patients in practice waiting rooms. The study enrolled 1,346 patients who screened positive on a standardized screener for probable depressive disorder in the prior 12 months. The screener included the “stem” items for major depressive and dysthymic disorders from the 12-month *Composite International Diagnostic Interview* (CIDI) (Wells, 1999; Wells et al., 2000) and items assessing depressed symptoms in the past month. Patients were defined as having probable disorder if they had 2 weeks or more of depressed mood or loss of interest in pleasurable activities during the last year, plus having at least 1 week of depression in the last 30 days. Screening occurred after an initial period in which practices assigned to collaborative care had received training and resources to implement collaborative care for depression, or received written guidelines on evidence-based depression treatment. Providers and patients were free to make treatment decisions as they would naturally, so that the study focused on the impact of providing training and resources for depression care. Follow-up depression outcomes of the 280 in the qualitative sub-study participants are presented across ten years (baseline, six months, twelve months, eighteen months, twenty-four months, four years and nine years) assessed with the screener measure of probable disorder (Wells et al., 2000), referring to the prior 6 months and deleting the dysthymia stem item.

Continuation Study

A continuation study was conducted at ten-year follow-up to understand patients’ experiences years after being identified with depression in primary care, across different ethnic groups. For this phase, all PIC participants who completed 9-year follow-up and were Latino or African American were invited to participate in the ten-year study, plus a random sample of Whites, stratified by initial geographic site and intervention status, to achieve a comparable distribution in these characteristics to the minority sample. The eligible sample for the qualitative interviews was 359. Among these, 280 completed at least one interview, and the average completion rate across the 3 interviews for those completing any interview was 88%. A stratified random sample of 34 transcripts were rated clinically to generate a fuller view of the need for care in this population of depressed primary care patients.

Recruitment

All participants were invited by letter and telephone follow-up to complete a series of 3 semi-structured interviews 1–2 months apart about their experiences in the prior month. The interviews included a set of screening modules followed by semi-structured questions and probes for modules having a positive response. The modules covered depressive symptoms, use of healthcare services, use of psychotropic medications, life stress events, proactive coping to avoid life stress, and positive events in the prior month. Interviews were conducted by trained staff who recorded participant responses using a structured note template. In addition, all interviews were digitally audio-recorded. For each module, the probes followed a “funnel” structure (Brod et al., 2009) beginning with a free list (e.g., listing symptoms experienced), grand-tour question (“tell me everything that happened”), and focused questions on specific aspects (What else was going on? Who was involved? What were you thinking? What were you feeling? What did you do?). Participants were also asked to compare or contrast this experience with a similar experience they had in the past. Each interview lasted about an hour, and within that time, interviewers focused on one or two

modules (and in subsequent interviews, focused on modules not already covered, such that the three interviews were one record).

Quantitative Analyses

For the quantitative analyses, we examined rates of depression in the total sample of 280. Data sources included variables from the original Partners in Care study baseline surveys on gender, ethnicity, age, whether or not US-born, education level at baseline; plus, having any insurance coverage and screening positive for depression at each time point, including the 9-year follow-up survey that initiated the continuation study. In addition, we used data on whether each participant screened positive for depression symptoms in that module for at least one qualitative interview. We used descriptive statistics to present characteristics of the overall sample, and summarize and illustrate main themes from the Module Review, Clinical Ratings, and Clinical Recommendations below.

Qualitative Analyses

For the qualitative content analyses and clinician ratings, we selected a stratified random sample of the 280 participants that had at least one interview, to achieve a sample of 6 participants for each gender-ethnic group (Latino, African American, and White men and women), balanced by intervention status (i.e. quality improvement or enhanced usual care practice). There were only 5 participants who self-identified as African American male, but one was determined in the interviews to be female and was excluded from this analysis. The study analysis is based on this stratified, random sample of 34 participants and their 96 interviews over three time periods six months apart.

Clinician Review

We developed a novel analysis approach, integrating clinical expert panel methods based roughly on the RAND appropriateness method for development of quality of care indicators (Wells et al., 1994) used for the stratified random sample of 34 participants (96 interviews). Each clinician read each case and answered a series of questions (see Appendix 1 for questionnaire), including describing stressors, turning points, current functioning, social network and clinical outcomes, including rating of depression, engagement in care, acceptability of care outcomes, coping, and suggestions for care. The clinicians included a Latina psychologist, a White male psychiatrist, a White female psychiatrist and a Latina internist. The main data source was the interviewer's structured notes supplemented by audio-tape review for confirmation. The approach included three activities per case: *Module Review*, *Clinical Rating*, and *Recommendations*. *Module Review* involved a structured review of all interview notes for a given participant, after which the clinician reviewer completed a structured form to summarize information about symptoms, services, medications, coping strategies, and positive events. After Module Review, each clinician completed a structured set of *Clinical Rating* scales and provided brief written justifications. Ratings were of whether the participant had severe depression (or other severe mental disorder); were engaged in needed treatment/services; acceptability of overall status; and effectiveness of coping. Response choices were yes/acceptable; probable/maybe; no/unacceptable. *Recommendations* were made by having each clinician identify gaps in care

and make recommendations for additional services or support when the clinician deemed these needed.

After completing independent assessments, reviewers discussed and reconciled major discrepancies (disagreements of more than 1 point out of 3) and finalized assessments, with 100% agreement for the 2 primary reviewers for all cases. Major themes were summarized by two authors (KW, JM) from Module Review, Clinical Rating justifications, and Recommendations for each ethnic-gender group. Themes and summaries were discussed by all team members to compare and test understandings and to identify key examples. For this analysis, intervention status is considered a design variable as groups were balanced in that status, but was not a main thematic focus.

Example Summaries

To illustrate richness of the qualitative interview data, we briefly summarize the 3 interviews for the first randomly selected African American female. In Interview 1, she noted in describing symptoms: “there’s something I’m looking for that I can’t get to—that would make me happy.” She described visiting a primary care provider who initiated Wellbutrin for smoking, which made her feel optimistic: “I’m more actively involved in getting better.” In interview 2, she noted that there was more to depression than smoking, and that her 15-year-old daughter had noticed her depression. She described conflicts with her 22-year-old son over his not working and drinking. She talked about her friend being hospitalized for a heart condition, reminding her of losing her father and brother, which had precipitated a prior severe depression. She noted: “It makes me realize how much I care.” In interview 3, her aunt had recently passed away and she described working on estate issues with her sisters and mother, talking over past conflicts. She then talked with her children about her concerns for them. “Things can change for the better,” she stated.

Community/Consumer Review

We also conducted a community-co-led discussion using a book club format to elicit views of consumers and other stakeholders, based on modifications of expert review methods for community stakeholders. This community-partnered “book club” with 24 individuals, including ethnically diverse men and women representing all 6 ethnic-gender groups for participant analysis, focused on a review of three cases. The members included providers, community members, mental health patients or consumers and academic researchers. The aim was to obtain diverse perspectives on a subsample of cases to inform clinician content analyses and ratings strategies. The approach was based on a “book club” format developed to stimulate participatory dialogue in a community-academic partnership (Lizaola et al., 2011). The group was co-led by an academic investigator and experienced community partner, and involved Module Review of 3 cases and listening to sections of audiotape, followed by open discussion. Research assistants and an investigator (EB) took notes that were reviewed for themes by community and academic group members.

The data sources and analytic sample include

Survey data for 280 PIC subjects (minority + stratified random sample of White) are included providing rates of depression over time. Interview data for 34 PIC subjects (random

sample stratified by gender, ethnicity) are provided to understand the depressive symptoms, use of healthcare services, use of psychotropic medications, life stress events, proactive coping to avoid life stress, and positive events in the prior month for participants. Content analyses are presented from clinician reviews of the narratives and community member reviews. In addition, clinical ratings were obtained for each case to identify clinical status and gaps in care.

Results

The quality improvement interventions, relative to usual care, increased the rate of guideline-concordant care (use of antidepressant medication above minimum dosages or use of specialty counseling for depression) by 10 percentage points, reduced the rate of probable depressive disorder by 10 percentage points, and increased rates of retention in employment over the first year (Wells et al., 2000). Over two years, the interventions reduced “depression burden days” and unemployment days. The quality improvement interventions had a modest overall effect on health outcomes at five years, due primarily to a very large effect on reducing the rate of probable disorder (over 20 percentage points) among minorities. (Wells et al., 2004a) The main effect of the quality improvement interventions on mental health and unmet need had ended by nine-year follow-up (Wells et al., 2008).

Table 1 describes the characteristics of the 280 participants in the longitudinal qualitative sub-study. As can be seen, nearly 80% were female, 70% of the Latino sample was U.S. born, and nearly half were married. Nearly 30% of Latino’s had lower than a high school education, as did less than 3% of African American, and 9% of White patients. Nearly 90% had health insurance. Nearly half of the African American and Latino patients, and nearly 40% of the White patients screened positive for major depression at the beginning of the qualitative study, 9 years following baseline.

Depression Rates Over Time

We examined the long-term depression outcomes of 280 sub-study participants across ten years. Participants completed telephone interviews with screeners for probable major depression at the following time periods: baseline, six months, twelve months, eighteen months, twenty-four months, five years and nine years. At each time point, over 40% of the respondents had probable depressive disorder (46%, 49%, 44%, 49%, 41%, and 45% respectively). Results showed that at the beginning of the qualitative interviews, about ten years after baseline, 65.8% reported significant depressive symptoms. We also examined intensity of the depressive episodes over time for participants. As such, we categorized participants as having probable depressive disorder at all six waves, depressed at half of the waves, or depressed at less than half of the waves. Results showed that 13.8% were depressed at all six waves, 35.6% were depressed at half of the waves, and 50.6% were depressed at less than half of the waves.

Symptoms/Depression History, Stressors, Engagement in Care, Coping, Positive Events

Table 2 presents a descriptive summary of the findings from the stratified random sample of 34 cases, indicating those who reported positive results in each category (i.e. had current

depressive symptoms, stressors, etc.). Common symptoms of depression were noted across genders and groups. Interestingly, White and African American females used the word depression while all males and Latinas used the term sadness. All participants were aware of multiple stressors in their lives. The most common stressors were financial/work and family/relationship stresses across all groups. Nearly three quarters of the participants were engaged in some type of care. With a few exceptions, the care providers were not mental health specialists, and ranged from primary care physicians to faith leaders to alternative care providers. The Latinas were least engaged in care. Just over half of the patients were taking medications for their depression. The patients perceived that anti-anxiety, sleep, muscle relaxants, and pain medications were also prescribed to help their mood. Life stress and coping strategies are summarized in Table 3. All but one respondent reported using coping strategies proactively to improve their mood. A large number of strategies were used, including using activities to cope (i.e. praying, walking, taking sick leave, trips, spending time with grandchildren) as well as cognitive strategies (i.e. working to stay calm, talking with others, thinking positive). Interestingly, avoidance was a coping strategy mentioned by members of each race/gender group except African American males. These strategies often allowed individuals to avoid a confrontation they felt unlikely to win. Participants also talked about positive events in their lives. Many participants talked about positive family interactions, including spending time with grandchildren and other family members. Improving health, such as stopping smoking or improving diet, was also listed as current positive events.

Clinical Ratings

Table 3 summarizes the clinical ratings of cases. The aim of the clinician ratings was to help identify patient needs that may not be currently taken care of within our systems of care. Across the 34 cases, 4 rating schemes, and 4 raters, there was only one rating for one case for which a clinician rating differed from another clinician by more than one point. Two raters completed a small number of ratings, and two raters (KW, JM) rated all of the interviews. After discussion, there were no differences in ratings between these two raters with complete ratings. Twenty-one of 34 cases were rated as likely to have a clinical depression at 10-year follow-up. Hispanic males and White females were more likely to be rated as clinically depressed, to have poor engagement in care, to have made unacceptable progress, and to have ineffective coping skills; although males generally were rated as having poorer engagement than females within ethnic grouping, and Latino females also tended to have coping skills rated as ineffective. There was variability within each group. Only 8 individuals of 34 (18%) had a clinical rating of acceptable status/progress from any clinician.

Recommendations

Of the 34 participants, 19 were judged to be clinically depressed, 7 had some depression, and 8 were judged not depressed. Quality of care was judged to be acceptable in 19 cases, equivocal in 9 and not acceptable in 6. Progress on depression treatment was considered acceptable in 11 cases, equivocal in 14 cases, and not acceptable in 9. The coping strategies used were considered effective in 16 cases, equivocal in 11, and not effective in 7. Of the 34 participants, 6 were rated by at least one clinician as not requiring recommendations for

interventions either because they were not depressed or because their care and/or overall status was adequate. For 28 of 34 individuals, recommended interventions included new treatment (medication and/or behavioral); treatment adjustment (adjusting medications, adding a focus on a particular behavioral or social issue); care coordination; social services; social support or social activities. All Hispanic males had a treatment recommendation from at least one clinician, including individual or group therapy, anger management or other behavioral intervention, antidepressant or other medication adjustment; and two also had recommendations for social support or activities, such as volunteer work or a support group. Two of four African American men were rated as okay or only requiring care coordination for existing services; and two had recommendations for treatment including couples or family therapy. Three White males had at least one clinician recommend a new treatment such as couples or family therapy or medication; and one other had a recommendation for treatment adjustment; and four had at least one clinician indicate that progress was acceptable and no recommendations were needed. Five Latino women were recommended for new treatment, three of which were also recommended for social activities; and one was viewed as okay/not needing recommendations or only recommended for social activities. Four of the African American women were recommended for treatment (two also for existing treatment adjustment or social activities); one for only treatment adjustment; and one for only social activities. There were five White women recommended for new treatment such as individual or group therapy or medication, with or without existing treatment adjustment or social services; and one for social support or activities only. Thus, across most ethnic groups, the majority were recommended for treatment or treatment adjustment, plus other recommendations for care coordination or social activities for most of the remainder.

Case Examples

To further illustrate the recommended treatment, we will discuss three cases. The first case fits within our earlier category of a participant who was depressed less than half of the evaluation periods throughout the study. In this case, the 57-year-old African American female who had intermittent mild depression received our recommendation for a short course of cognitive behavioral therapy. Throughout her three interviews she complained of stress at work and home. She complained of a difficult supervisor and feeling responsible for all work at home, as her husband was somewhat debilitated from a stroke. She also felt that her mood was highly affected by the amount of pain she felt from having arthritis. She had been on an anti-depressant for eleven years and felt that it helped with her mood. She saw a psychiatrist for her anti-depressants at one point, but received them from her primary care provider for many years. She did try once to get a mental health consult but found the system too confusing.

She had a supportive husband, although he was disabled by a stroke, and two sons she described as wonderful. She continually struggled with stress, pain, and sleep problems. She also stayed on anti-depressant medications that helped her maintain her mood, but complained in the last interview that her insurance company switched her to an antidepressant that was not effective for her. She did not have any mechanisms for dealing with arthritis pain other than major pain medications.

This participant was generally tense and anxious and struggled with mood, although she was quite clear that her mood over the three interviews had improved since her initial diagnosis. She could definitely benefit by therapy to help her deal more effectively with her pain and the stress she perceived in her life. Our recommendation was a short course of cognitive behavioral therapy around pain management and coping with stress.

The second case is a 54-year-old Latino male who was recommended to get a longer course of psychotherapy focused around his chronic depression. He had been depressed at more than half of the nine interviews, but not all of them. He had become depressed secondary to an injury that ended his work career almost ten years earlier. He spent most of his time at home, feeling useless and very dysphoric, and complaining bitterly of pain. He got along well with his wife and sons, although one son was often in jail. Over the course of three interviews, he was depressed in the first and third interviews, but much happier during the middle interview. At that time, he was visited by his 9-year-old grandson. He spent his days entertaining his grandson by taking him fishing, hiking, and cooking for him. When asked, he volunteered that he didn't experience so much pain while his grandson was visiting, but it returned as soon as his grandson left. This case was very similar to others treated by one author (JM) in a clinic to treat depression at San Francisco General Hospital. This patient likely was unsuccessful at work, yet firmly believed he should work. The injury resolved his problem of being unsuccessful at work, but left him needing to be "ill" in order not to feel guilty about not working. Thus, his days were spent being ill. When visited by his grandson, he felt better. Through psychotherapy, this patient would likely be able to learn that he does not need to spend all of his time being ill, even if he is on disability. He would be encouraged to engage in pleasant activities that would likely improve his mood, as was true when his grandson was visiting.

Our third illustration is of a 73-year-old White female with increasing serious depression. She had been depressed at all nine time periods. This woman had an extremely stressful life. She had been taken care of by her husband most of her life, but he experienced a series of strokes rendering her the caretaker for her husband. In addition, she had a daughter with multiple sclerosis who was difficult to manage and living in a substandard care setting. She felt responsible for her daughter but unable to help her, as the daughter was not responsive to her concerns. Her son had cancer, and she felt that he was not taking proper care of himself. As her stress level increased, she experienced more significant bodily pains, including back and stomach pain. She received a recommendation for referral for medications as well as supportive psychotherapy. Because of the depth of her depression and the seriousness of her ongoing stress, we felt that she needed combined medication and supportive therapy.

Community Book Club Discussion

After reviewing cases, the consumer and family member participants in the book club remarked that it was important to emphasize the positive and that people are "surviving and coping even though they are stressed." They noted that participants who braved difficult circumstances and moved ahead with their lives could be considered heroic; sometimes people couldn't tell they were recovering and did not know how to discuss their progress; and participants who were taking medications often felt they were not getting the support

they needed in the community for that treatment. The implication is to provide greater community or family support for patients struggling to find social support for having treatment. The group also noted that for many participants, simple tools such as taking a walk were powerful coping strategies. Providers and consumers wondered if the participants understood that they might suffer from a treatable mood disorder. Participants also commented that people were struggling to cope with many stresses and that when coping failed, they were often overwhelmed. They also observed that the listeners in the book club wanted to convey, “I hear you, I understand you,” and that it felt important for those involved with depressed individuals to take the time to listen to what people were actually saying about their lives and needs for support.

Discussion

This novel analysis of 10-year follow-up data combining survey results, clinician review and rating, and community dialogue produced observations that may inform or raise questions for further research and ongoing treatments for depression. First, many patients initially identified as depressed 10 years earlier in primary care continue to struggle with depression over long periods of time. Despite this sample being part of a positive trial of a quality improvement intervention, over 10 years of assessments, nearly half of the participants were depressed at any one time. As clinicians, we felt that the majority of the cases (28 of 34) needed additional treatment. In our reviews, we felt confident that most of these individuals could be living a higher quality of life if they could be provided quality depression care. Our community partners also emphasized the importance of respecting the coping of these individuals, many of whom were under a great deal of stress. Ideally, clinicians should both support individuals around their stress and accurately reflect back to them the strength they have shown in coping with multiple stressors.

Most participants in all ethnic and gender groups were recommended by the study clinician reviewers for some form of active treatment or treatment adjustment, such as counseling, CBT or medication. Many were recommended for simple daily activities such as staying active, communicating, participating in pleasurable activities, accepting or giving affirmation, or obtaining information or addressing stigma. These issues might be suitably addressed by case workers, community health workers, or other social or human services providers.

Many individuals were coping with multiple stresses, many of them related to aging, such as physical health problems and raising grandchildren, and this pattern was true across ethnic and gender groups. The overall pattern of the narratives suggested that depression, physical health, life events, and interpersonal relationships among family and at work, combined to yield ongoing, moderate to severe stress for most groups. Some minorities described ethnic-specific experiences such as work-related discrimination. Many on medications or other formal treatment described lack of support or understanding among close family members or friends. Yet, most people, while having multiple stressors were able to articulate coping strategies, and a few had achieved a kind of turning point for a higher level of coping, while the majority were just surviving or getting along. The men in this sample appeared to struggle more with anger and irritability issues, while women were somewhat more likely to

talk about controlling or abusive spouses or significant others. Many of the most successful coping strategies spontaneously reported by patients doing somewhat better included simple activities such as taking walks or maintaining contact with family members.

Latinos, especially females, seemed to be especially unlikely to describe successful engagement in care when having symptoms. From our clinical experience with this population, this inability to engage in care could be for a number of reasons. In our experience, Latinas are often reluctant to identify their own mental health needs as a priority because they are so involved in caring for their families. We have also found that Latinas often work at jobs that do not have stable, predictable hours allowing them to come to care. Finally, transportation and babysitting are major barriers to care for Latinas. (Nadeem et al., 2007)

This study has a number of notable limitations. The study largely relies on self-reported data. The qualitative study relies on a subset of the original study, including all minorities and a matched White sample. Our in-depth analyses rely on a small sample of 34 randomly-selected individuals. Our Latino sample was primarily US-born and many were from Mexico, so the results may not generalize to other groups of Latinos. Finally, our community and clinical reviews were based on a small community sample and much of our clinician data relied on two clinicians.

Conclusions

These data demonstrate important gaps in our understanding of long-term courses and outcomes in depression, including among populations that experience disparities. Among others, the hypotheses for future research generated by these results include that strategies for maintaining engagement in treatment and facilitating re-entry into treatment, such as greater family or community support for care, may be important for supporting long-term outcomes. Findings also suggest that attention to multiple life events (e.g. physical health, family function) in the course of adult development may help to match depression treatment to patient perceptions of need. Finally, supports for daily activities may serve critical adjunctive functions in clinical treatment for depression or support improvement and recovery from depression on their own as complements to care. Studies that can sketch the lived experience of depression within its social context can be used to develop key features of novel approaches to improving long-term outcomes.

APPENDIX 1: Partners in Care/Role of Social Networks in Treatment Engagement for Minorities

Interview Summary Form

Date Summary Completed:

Completed by:

Participant Code:

Total No. Interviews:

1. In your opinion, what is most striking or important about this case?
2. *Personal Background Summary*

- 2a. Impact of financial stress:
- 2b. Stigma/discrimination issues:
- 2c. Positive/negative turning points:
3. *Mental & Physical Health Summary*
- 3a. Substance use issues (alone or with network):
- 3b. Impact of treatment/providers:
- 3c. Barriers to treatment/care:
4. *Social Network Summary*
- 4a. Connectivity/embeddedness of ties:
- 4b. Romantic partner role:
- 4c. Loneliness and/or social isolation:
- 4d. Ambivalence in major relationships:
- 4e. Marked change in social network over time:
5. **Clinical Notes:** Based on *summary, interviews, and/or "report card" review*
- i. Does this person have a clinically significant depression at one or more interviews? (*Circle one only*)
- a. Definite yes b. Probable-maybe c. Definite no
- Brief explanation:
- ii. How acceptable is this person's care or engagement in care? (*Circle one only*)
- a. Acceptable-meaningful b. Equivocal c. Unacceptable/problematic
- Brief explanation:
- iii. How acceptable is this person's overall progress/outcome course? (*Circle one only*)
- a. Acceptable/reasonable course b. Equivocal c. Unacceptable/could be much better
- Brief explanation:
- iv. How effective/adaptive is this person's coping given their illness and stressors? (*Circle one only*)
- a. Effective/adaptive b. Equivocal c. Not effective/adaptive
- Brief explanation:
- v. If you could make one suggestion to this person what would it be?
6. **Community Notes:**
-

Instructions for Completing Summary

After reading each of the interviews for one respondent, enter the header information at the top of the page. Enter the date, your name, the case id, and the total number of qualitative interviews with the respondent that you reviewed. Next, fill in text to summarize the main aspects of the interview. Write a paragraph (three or four sentences) to summarize the main boxes. Write a phrase or two to summarize the sub-topics below the boxes. If there was no information about one of the sub-topics, leave the line blank.

1. **Most Striking:** Summarize in a sentence or two whatever you remember the most about the interview.
2. **Overall Personal Summary:** Summarize whatever details are in the interview about who the person is. Include aspects about age, gender; race/ethnicity; veteran status, marital status, living & work situation, # children/grandchildren, major events in the person's life.

- 2a *Financial Stress*: Describe any concerns about financial problems.
 - 2b *Stigma/discrimination*: Summarize any discussion of the respondent feeling stigmatized due to illness/etc. or experience/feeling of being discriminated against.
 - 2c *Turning points*: Describe any mention of events that have changed their life for better or worse.
3. **Mental/Physical Health Summary**: Summarize the mental/physical health issues participant is dealing with, and how are they coping with it, including what type of professionals they are consulting for help/treatment.
- 3a *Substance use*: Summarize discussion of use of alcohol/drugs/etc. alone or with others.
 - 3b *Treatment*: Summarize how treatment is affecting respondent
 - 3c *Barriers*: Summarize factors that limit the respondents receipt of treatment
4. **Social Network Summary**: Summarize the discussion of supportive attributes/ individuals; undermining attributes/individuals; whether & how ties facilitate or sabotage treatment seeking/adherence/engagement; whether & how ties facilitate or sabotage coping
- 4a *Connectivity*: Summarize the amount of connections among social network members
 - 4b *Romantic partner*: Summarize the role of a romantic partner in the respondent's life
 - 4c *Loneliness/isolation*: Summarize discussion of loneliness/isolation
 - 4d *Ambivalence*: Summarize mixed feelings/experiences with major network members
 - 4e *Network Change*: Summarize discussion of how network has changed over time
5. **Clinical notes**: To be filled in by trained clinician. Evaluation of severity of depression/symptoms as described by the respondent, appropriateness of treatment engagement, effectiveness of coping, and evaluation of how well the respondent is doing.
6. **Community notes**: Any comments about respondent provided by community partners.ap

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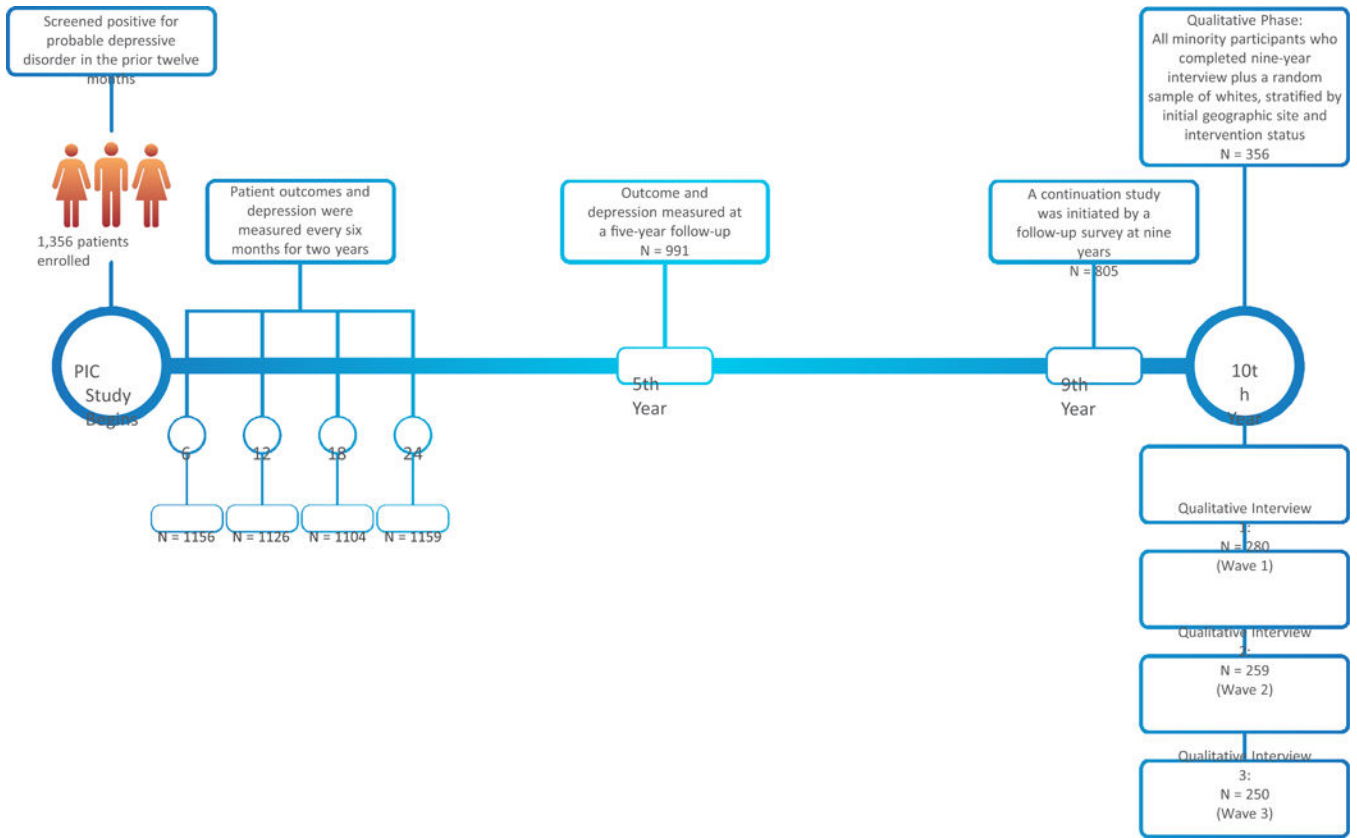


Figure 1.
Graphic representation of the Partners in Care (PIC) study.

Table 1

Characteristic of Patients by Race/Ethnicity

Variable	Overall (N=280)	African American (N=37)	Latino (N=157)	White (N=86)
Age at 1 st qualitative interview	53.4±12.7	52.7±12.3	52.5±12.4	55.4±13.2
Female Sex	80.7%	86.5%	77.7%	83.7%
US-born	81.4%	100.0%	70.5%	92.9%
High School, PIC Screener				
<High School, PIC Screener	20.0%	2.7%	29.9%	9.3%
High School, PIC Screener	80.0%	97.3%	70.1%	90.7%
Married, PIC 9 year	56.4%	43.2%	59.2%	57.0%
Had health insurance, PIC 9 year	87.8%	94.6%	86.5%	87.2%
Chronic disease count from a list of 19, PIC screener	2.3±1.9	2.2±1.3	2.4±2.0	2.3±2.0
Screened major depression PIC 9 year	45.4%	45.9%	49.0%	38.4%

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Table 2

Positive outcomes by patient ethnicity and gender

Participant Ethnicity & Gender (N)	Depression: Current and Prior Status & Symptoms	Current Stressors	Current Services Engagement	Current Medications	Current Use of Proactive Coping	Current Positive Events
Latino Males (6)	6 current: 2 all, 2 half and 2 0-1 prior wave; anger, desperate, lonely, no energy, sad, sick, pain	6 multiple: financial & health issues for self or family; inter-personal conflict	4: neurology, counselor, primary care MD, nurse; access issue: counselor leaves, delay in care	3: anti-depressants or pain medication	5: anticipate, prayer, stay calm, avoid conflict; compromise, confront, games, walk	4: improve marriage, camping, graduation, see grandkids
African American Males (4)	3 current: 2 all, 1 half, 1 0 prior wave; memory, fatigue, anxiety, lose interest, cry, weight, violent, sleep	4 multiple: sickness of self or family, argue with spouse, son prison time	4: primary care, deacon, psychiatrist, surgeon; 3 find helpful.	3: anti-depressant ³ found helpful but family members mixed response	4: Bible study, talk to others, warn others, not jump to conclusions; get care, stay calm, sick leave, trips	4: graduation of grandson, read about raising kid, enjoy study interview
White males (N=6)	4: 1 all, 3 half, 2 0 prior wave; anger, weight, cry, sad, lonely, withdrawn, nervous, stress, worry, life tedious	6 multiple: legal, financial, work, death of friend or parent, conflict with others, friend jailed, health of self, spouse	5: medical staff, social worker, faith leader, visiting home nurse, self-help group	4: sleep med, anti-depressant, anti-anxiety; 2 found helpful; family not supportive	6: confident, avoid, activity, think positive, compromise, trip, see others, get involved, talk to provider	3: anniversary, plan trip, find tenant, health gain for self, spouse
Latino Females (N=6)	5 current: 2 all, 2 half and 2 0-1 prior waves Tired, lazy, pain, cry, sleep, lose control, weight, sad, blue or lack of interest	6 multiple: financial, health of self or family, estate, family event, spouse drinking, painful memory, parent death	3: primary care, Alonon, mental health specialist, noted as not helping.	1: current medication and 1 in past	6: avoid negativity, confront, move, work, talk, cut spending.; see grandkids, learn new language, develop plan	3: apply for loan, new business, family holiday
African American Females (N=6)	5 current: 2 half 4 0-1 prior wave; tired, guilty, sleep, depressed, no interest, isolation, loneliness, weight, bodily pain, anger, focus, shut down, belittled or betrayed.	6 multiple: health of self or others, grief/estate issues, child leaves home, foreclosure, housework or work, death of pet, not exercise, spouse or family conflict	5 and 1 scheduled: self-help or Narcanon, primary care, orthopedist, acupuncture, faith leader, psychiatrist	6: anti-depressant, muscle relaxant, sleeper, helped some 3 had side effects	6: talk, vent, face issue, avoidance, information, stay hopeful	6: stop smoking, job interview, visit family, take vacation, meditate, new pet, day off, laid off, family or friend support, health gain, money, games
Participant Ethnicity & Gender (N)	Depression: Current and Prior Status & Symptoms	Current Stressors	Current Services Engagement	Current Medications	Current Use of Proactive Coping	Current Positive Events
White Females (N=6)	4: 4 half and 2 0-1 prior waves; trapped,	6 multiple: financial or car trouble, illness of self	4 services now 1 past: faith-based groups, primary care, social worker,	3: anti-anxiety, anti-depressant, medication	6: control situation, avoid	visit grandkid, discard son's picture, health gain of

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Participant Ethnicity & Gender (N)							
Depression: Current and Prior Status & Symptoms	lost, upset, tired, frustrated, sad, angry, sad, crying, depressed, weight problems, loss of control, bodily pain, sleep problems						
Current Stressors	or family, buy house or move, anniversary of loss, argue, family member arrested, fear of family member, weight gain						
Current Services Engagement	alternative and other healthcare providers						
Current Medications	switch; all favorable, 1 has side effects						
Current Use of Proactive Coping	conflict, solve problem, talk to friends, live day to day, lose weight						
Current Positive Events	spouse; visit from daughter or friends, buy house						

Table 3

Clinical Ratings by Ethnicity and Gender

Gender/Race Case Number (Depression history prior surveys, 6 waves)	Clinical Depression (prior month) 1=yes 2=equivocal 3=no	Care Quality 1=acceptable 2=equivocal 3=not acceptable	Progress 1=acceptable 2=equivocal 3=not acceptable	Coping 1=effective 2=equivocal 3=not effective	Coping Summary (Key challenges and strategies)	Recommendation 1=add treatment 2=adjust treatment 3=social activity/care coordination 4=OK
Latino Males						
Case 1 (not depressed prior waves)	1	3	3	2	Maintained marriage despite decline in health self/spouse	1: Counseling/CBT; Possible meds for Depression/anxiety
Case 2 (depressed half of prior waves)	1	1	1	1	Learned to manage anger, post- deployment PTSD in VA therapy, saved 3rd marriage	2: Adjust meds; Consistent counseling for PTSD/anger
Case 3 (not depressed prior waves)	3	1	1	1	Conflicts with coworkers, friend; anticipated, walks	1: Counseling for work stress; Anger management; consider Cognitive therapy.
Case 4 (depressed all waves)	1	3	3	3	Pain and raising grandchildren cut time with wife; stopped drinking	1: Support group; CBT for negative thoughts
Case 5 (depressed half of prior waves)	1	3	3	3	Used alcohol and marijuana, suicidal post-deployment; no treatment	1: Treatment for depression/PTSD/ substance abuse (VA)
Case 6 (depressed all prior waves)	1	2	2	2	Serious financial issues; enjoys grandchildren and able to set limits on son's demands	3: Volunteer work/Support group or brief therapy for coping
African American Males						
Case 1 (depressed all prior waves)	2	1	1	1	Had dementia and felt lonely and confused but found comfort in family and church	3: Family support/Primary care outreach
Case 2 (depressed half of prior waves)	1	1	2	2	Bipolar illness and anger issues; work discrimination but medications helped and psychiatrist gave tips on coping	1: Couples therapy; Techniques to cope with lethargy
Case 3 (not depressed prior waves)	3	1	1	1	Health problems of a grandchild; applied positive thinking, took trips	4:OK
Case 4 (depressed all prior waves)	1	1	2	1	Discrimination, argues; son in prison; applied disability; trip	1: Anger management/Behavioral activation; Couples therapy; Social activity/support
White Males						
Case 1 (depressed all prior waves)	1	3	3	3	Paranoid/mania; legal issues; near homeless, little effective coping	1: Bipolar evaluation/treatment (meds; family intervention) Board and Care

Gender/Race Case Number (Depression history prior surveys, 6 waves)	Clinical Depression (prior month) 1=yes 2=equivocal 3=no	Care Quality 1=acceptable 2=equivocal 3=not acceptable	Progress 1=acceptable 2=equivocal 3=not acceptable	Coping 1=effective 2=equivocal 3=not effective	Coping Summary (Key challenges and strategies)	Recommendation 1=add treatment 2=adjust treatment 3=social activity/care coordination 4=OK
Case 2 (depressed half of prior waves)	2	1	2	2	Anger issues; losing contact with kids; church group support; still lonely	2: Continue church; Cognitive therapy to improve relationship with kids
Case 3 (not depressed prior waves)	3	1	1	1	Stable; planned a vacation; sleep issues	1: Sleep cognitive therapy
Case 4 (depressed half of prior waves)	3	1	1	1	Health issues, lost friend, kid conflicts; cancer support group	4: Encourage to feel OK
Case 5 (depressed half of prior waves)	1	2	2	2	Friend jailed; laid off; surgery, meds, visiting nurse help	1: Family support group; Re-evaluate for meds; Consider CBT
Case 6 (not depressed prior waves)	3	1	1	1	Wife health; got support; set limits; enjoyed activities	4: Better diabetes self-control; enjoy life
Latino Females						
Case 1 (depressed all prior waves)	1	2	3	3	Often suicidal; not describe coping strategies	1: Therapy, probably also meds
Case 2 (depressed half of prio waves)	1	2	1	1	Stopped meds; self-help groups; losses but felt she handled well	3: Support group social activities/PCP referral to therapy
Case 3 (not depressed prior waves)	1	1	3	3	Suicidal after mom's death; withdrawn	1: CBT for grief; Med adjustment
Case 4 (depressed all prior waves)	2	2	2	1-2	Family conflicts; caregiver for grandkid; no coping described	1: Couples or individual Therapy; social group; Med evaluation
Case 5 (depressed half of prior waves)	2	1	2	1	Financial stress but spending less; closed spouse's account	1: Continue Alonon; Individual supportive therapy for coping
Case 6 (not depressed prior waves)	3	1	1	1	Many stresses; bad memories; workshop; cruise	3: Social support; Contact with daughter
African American Females						
Case 1 (not depressed prior waves)	2	2	2	1	Sick friend; aunt died; family conflict; but quit smoking; reconciled with family; positive	1: Referral for CBT evaluation for sleep; Psychological support
Case 2	1	1	2	1	Church services, self-help, own coping skills	1: Therapy for reality, withdrawal; medication adjustment

Gender/Race Case Number (Depression history prior surveys, 6 waves)	Clinical Depression (prior month) 1=yes 2=equivocal 3=no	Care Quality 1=acceptable 2=equivocal 3=not acceptable	Progress 1=acceptable 2=equivocal 3=not acceptable	Coping 1=effective 2=equivocal 3=not effective	Coping Summary (Key challenges and strategies)	Recommendation 1=add treatment 2=adjust treatment 3=social activity/care coordination 4=OK
(depressed half of prior waves)						
Case 3 (not depressed prior waves)	2	2	2	1	Took vacation and a day off	1: Meds consultation; Brief therapy for coping
Case 4 (not depressed prior waves)	3	1	1	1	No coping described	3. Social group/therapy
Case 5 (not depressed prior waves)	1	1	2	2	Daughter tried suicide, car stolen, husband no job; focused on next steps	1: Therapy for support; Move in with mother
Case 6 (depressed half of prior waves)	1	3	3	2	Many events, little coping described	1: CBT, med evaluation Social services for Finances, family
White Females						
Case 1 (depressed half of prior waves)	2	1	1	1-2	Anxious; saw granddaughter; Bible study but felt excluded	1: Stay on SSRIs; CBT for coping and communication skills
Case 2 (not depressed prior waves)	1	2	3	2	Interpersonal and health problems; meditated, alternative care	1. Medication or CBT; Social services/ Caregiver support
Case 3 (not depressed prior waves)	1	3	3	3	Many stresses; No coping described	1. Therapy for anxiety; antidepressant or change sleep meds; Couples work
Case 4 (depressed half of prior waves)	1	1	2	2	Family conflicts; "divorcing" in-laws	1: CBT/behavioral activation; Family therapy/support
Case 5 (depressed half of prior waves)	3	2	2	2	Small steps to cope; "got along"	3: Support to deal with husband/social activities/support group
Case 6 (depressed half of prior waves)	1	1	2	3	Zolofl helped; got rights to raise her grandchild	1: CBT for coping and reality; Adjust meds as needed