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Qualitative Research

Bipolar disorder in primary care: a qualitative study of clinician and patient experiences with diagnosis and treatment

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Abstract

Objective. To understand primary care patients' and clinicians' experiences with diagnosis and treatment of patients with bipolar disorder in primary care.

Methods. We conducted a qualitative study using thematic content analysis of individual interviews with nine primary care clinicians and six patients from Federally Qualified Health Centers to understand their experiences with the diagnosis and treatment of bipolar disorder.

Results. Themes of bipolar disorder detection, referral to specialty mental health care and medication treatment emerged from individual interviews with primary care patients and clinicians. Clinicians and patients faced challenges deciding to continue with care in primary care that is easier to access, but less intensive, than specialty care that can be harder to access but at times of higher quality.

Conclusions. Potential next steps in research include identifying ways to support primary care clinicians in detection of patients with bipolar disorder, and strategies to support treatment of patients in primary care with easier access to specialty care including consultation in primary care or co-management with specialty care.

Key words: Bipolar disorder, collaborative care, depression, primary care, rural health, safety net.

Introduction

Bipolar disorder I and II occurs in up to 4% of primary care attendees, though the prevalence is elevated in safety net settings or in patients already presenting with a psychiatric complaint (1,2). Additionally, bipolar disorder symptoms can exist on a spectrum with individuals experiencing varying degrees of symptoms (3), and bipolar spectrum features such as increased motor activity, hypersomnia, hyperphagia or irritability have been reported in clinical samples of individuals diagnosed with major depression presenting for treatment in primary or specialty care settings (4).

Many individuals diagnosed with bipolar disorder or with bipolar spectrum symptoms experience chronic depressive symptoms which impair functioning and reduce quality of life (5–7), in addition to less frequent manic and hypomanic episodes characteristic of

bipolar I and II disorder, respectively. Existing treatments for bipolar disorder effectively treat depressive (8) and manic (9) episodes, prevent mood episode recurrence (10,11) and improve overall functioning and quality of life (12).

Many individuals with bipolar disorder do not receive effective treatments, particularly early in the illness course where many individuals experience a 6- to 8-year gap between symptom onset and diagnosis (13,14). Undetected bipolar disorder is associated with functional impairment, reduced quality of life and premature mortality from injuries and chronic medical illness (15–17), highlighting need for accurate diagnosis and high quality of care for individuals with bipolar disorder.

Earlier diagnosis and treatment of bipolar disorder could occur for some in primary care. Patients with unrecognized bipolar disorder may initially present to primary care for care of other medical problems, care of misdiagnosed major depression, or with symptoms related to anxiety or substance use, which are common in patients with bipolar disorder (1,16–18). Additionally, patients previously diagnosed with bipolar disorder at a mental health clinic or hospital may return to primary care, often unaccompanied by extensive documentation or a comprehensive treatment plan, making accurate recognition of bipolar disorder important even in those already diagnosed (19).

In the USA, as many patients with bipolar disorder report receiving treatment in primary care settings as in specialty mental health care settings (18,20). This is even more pronounced among those with subthreshold bipolar disorder, where the majority of those seeking treatment in the preceding year presented to primary care settings (18,20). Individuals receiving treatment in primary care can present with high symptom burden (21) but are less likely to receive high quality of care such as treatment with a mood-stabilizing medication (16). Although primary care physicians have reported perceiving patients with bipolar disorder as complex (22,23), a more in-depth understanding of clinicians' experiences has been unexplored.

Using individual interviews, we sought to understand primary care patients' and clinicians' experiences with diagnosis and treatment of bipolar disorder in primary care. Understanding the barriers patients and clinicians face in primary care could lead to strategies to improve recognition and quality of care for individuals with bipolar disorder in primary care.

Methods

We conducted a qualitative study of individual interviews with primary care clinicians and patients from Federally Qualified Health Centers (FQHCs) to understand their experiences with diagnosis and treatment of bipolar disorder. FQHCs are safety net primary care clinics. This report follows Standards for Reporting Qualitative Research (24). Our study was exploratory and used an inductive approach using thematic content analysis to identify themes in the data (25,26). The Institutional Review Boards at the University of Arkansas for Medical Sciences (UAMS) approved data collection and the University of Washington approved data analysis procedures for this project.

Researcher characteristics

Investigators include two physicians (authors 1 and 3) who work in primary care and two social scientists (authors 2 and 4). Interviews were conducted by two male investigators, authors 2 and 3. Authors 2 and 3 conducted rapid data analysis and presented results to FQHC stakeholders (patients and clinicians) tasked with conducting quality improvement activities to improve access to evidence-based treatments for patients diagnosed with bipolar disorder. This provided an opportunity for theme checking of the rapid analysis. Authors 2 and 4 conceived the study and recruited clinics. The investigators were trained in qualitative methods through coursework and past experience conducting qualitative research. Participants knew the investigators were researching individuals' experiences with treating or receiving treatment for bipolar disorder in primary care settings.

Context and sampling strategy

This study occurred as part of an Academic Community Implementation Partnership (ACIP) between UAMS and rural FQHCs in Arkansas during 2010–2017. The ACIP focused on identification, adaptation, adoption and evaluation of evidence-based practices for patients with bipolar disorder. The medical director, nursing director and two patients from six primary care clinics participating in ACIP were invited to participate in interviews in 2012. We sought medical and nursing directors to gain representative overviews of current clinical practice and barriers and facilitators in each site. Invited patients were identified by clinicians based on having been diagnosed with a complex mood disorder either bipolar disorder or treatment-resistant depression (due to clinician diagnostic uncertainty). Some patients did not attend scheduled interviews for this study. Interviews from five sites were completely recorded and transcribed for inclusion (one site's interview was not recorded).

Data collection

Interview guides were developed by investigators to initially ask open-ended questions about participants' experiences, followed by questions on specific topics such as how psychiatrists could help primary care clinicians. Interviews occurred on-site in the FQHCs, included one participant (clinician or patient) and two investigators (one interviewing and one taking field notes) and lasted between 30 and 60 minutes. Interviews were audio-recorded and later transcribed. Transcripts were entered into Atlas.ti for data organization and sorting. Data collection intent was to understand patient and clinician perspectives for subsequent intervention development. Data saturation was not specifically sought due to interviewing preselected types and numbers of stakeholders. The purpose was to use their feedback in an intervention development process occurring rapidly. Recruiting and interviewing additional patients and clinicians to achieve saturation for both groups was beyond the scope and feasibility of this study.

Data analysis

The two interviewers conducted iterative analyses after each interview using field note review and open-coding to resolve differing impressions through discussion, to modify interview guides used in subsequent interviews and to improve trustworthiness (27). Data analysis was conducted by author 1 after all interviews were completed and transcribed data were available. Patient and clinician data analysis occurred concurrently because of investigators' interest in understanding patient and clinician experiences with diagnosis and treatment. Open-coding using thematic content analysis was used, and codes were sorted into categories. Meetings between author 1 and author 2 occurred iteratively to discuss codes and categories and to review emerging themes (26). Results were presented to a multidisciplinary group of primary care and psychiatry clinician-researchers for feedback, and suggestions from the group were incorporated to enhance trustworthiness.

Results

Interviews with 15 individuals were included. Interviewees included nine clinicians (five physicians and four registered nurses) and six patients with clinician diagnosis of bipolar disorder or treatment-resistant depression. Three themes emerged from the data: detection of patients with bipolar disorder, referral to specialty care and medication treatment. Data analysis uncovered barriers and facilitators of each theme within the data. Quotes supporting each theme are below, with additional supporting quotes in Table 1. Quotes are annotated with C or P if stated by clinician or patient, with associated ID number.

Theme 1: detection of patients with bipolar disorder

Barriers

Primary care clinicians described problems detecting patients with bipolar disorder including patient-related barriers such as patients presenting intermittently for urgent problems or presenting regularly for treatment but for other chronic illnesses taking up visit time, clinician-related barriers such as lack of understanding of bipolar disorder course, and systems-related barriers such as uncertainty about how to best support workflow (e.g. screening) to detect patients with bipolar disorder.

> Some of the walk-ins are just here for acute type treatments. So you asked me if they go unrecognized, in that case yeah they may go unrecognized. (C1)

Patients reported barriers including stigma and not feeling listened to by primary care clinicians:

> My doctor didn't believe in diagnosing me with my bipolar disorder. He thought it was an over diagnosed disease. (P4)

Facilitators

When primary care clinicians suspected bipolar disorder in a patient, clinicians saw value in team-based assessment, including use of screening measures administered by clinic staff, information reported from patient family members, and obtaining past treatment records. Additionally, one clinician described that tracking patients over time helped to encourage patients to follow-up and helped facilitate detection and diagnosis due to the opportunity for multiple observations of symptoms:

Table 1. Additional quotes supporting themes

	Participant	Quote
Theme 1: Detection of patients with bipolar disorder	Clinician	'Okay so the current PHQ-9 we have, so is that just for depression? So it's not for bipolar?' (C6) 'I guess of course I go in and think somebody may or may not have a bipolar disorder you know I could come out and say do the screen on this patient.' (C1) 'I think the [clinician] is going to trust what the screener is doing.' (C3) 'They are coming in to get their… hypertensive meds, or diabetes meds, and just kind of go with the flow.' (C4)
	Patient	'I don't really think that they believe me. That's bad. You know, when you don't think nobody believes you.' (P6) '[My sister and I] live together, she knows [about my bipolar disorder] and it's really hard for me to talk to someone face to face so my sister was my voice.' (P5)
Theme 2: Referral to treatment in specialty care	Clinician	[Problems are] the stigma associated with it… [and] they're very shorthanded staff-wise so it's still a long wait time [for an appointment]… so in the meanwhile they're still back with me or us [in primary care]. (C7) 'In a setting I guess in [specialty care] they're probably going to allow much more time like 30 or 40 minutes for one patient and you can give it time.' (C1) 'That's why they have specialists. I'm not a specialist, I'm an internist and you're past mark one of comfort.' (C7) '[Communication is] not good at all. It's difficult to get their notes, to see exactly what's going on. Often times the patient will just present with this slip saying "I need these labs. This patient is on this medication." And that's it.' (C5) 'Almost half the battle is getting them to see someone.' (C5)
	Patient	'They had me see [the psychiatrist] and he's the one that, when I saw him, he's the one that come up with [the diagnosis of bipolar disorder].' (P6)
Theme 3: Medication treatment	Clinician	'I see a lot of depression and some of it may be missing bipolar, but I'm comfortable with treating depression.' (C7) 'We try to provide [medication] treatment if we can't get them in.' (C5) 'It makes me feel like I have a little bit more evidence if someone else is saying, 'Hey, I recommend either this one or this one,' because that just helps me out.' (C3) '[To feel comfortable about diagnosis] to even have somebody on the computer screen right there, it would just take a couple… patients, and then our providers would be more comfortable doing things on their own.' (C3)
	Patient	'[My treatment] has never been adjusted. It's always been the same. I think that once they put you on a medication they just kind of say "Okay, she's on that. All of her problems are taken care of." It's never gone back to be checked on. It's just left alone.' (P4) 'Let me tell you I would have been hospitalized if it wasn't for [the care manager in primary care], I was just at the lowest I ever felt in my life and I couldn't control it.' (P5) 'My blood pressure was high, so [my primary care physician] would give me medicine for my blood pressure, so I would have to come every three months for her to evaluate me and that's when I would say something [about bipolar disorder treatment].' (P6)

> One of the things we're moving toward, is to track all patients. (C1)

Patients also reported value in tracking their course over time and having family members talk with clinicians. One patient described how tracking response to initial treatment with an antidepressant medication and discussing symptoms with a clinic care manager helped the patient understand how symptoms were due to bipolar disorder rather than major depression:

> [The care manager] helped me to understand that the citalopram or whatever it is, that that wasn't helping me because I needed something for my bipolar…. (P5)

Theme 2: referral to treatment in specialty care

Barriers

Primary care clinicians described their rationale on deciding when to refer a patient with bipolar disorder from primary care to specialty mental health care such as when a patient's care needs exceed the clinician's comfort; however, clinicians also reported reasons for needing to treat patients in primary care such as poor communication about patients between specialty mental health and primary care, challenges to referral including stigma, and needing to convince some patients to agree to referral:

> I don't really hear from [specialty mental health about patients]. Maybe one time a year. (C8)

Patients completing referral from primary care to specialty mental health may face barriers to accessing ongoing treatment in specialty care. For example, one clinician described, compared with specialty care, appointments in primary care were more easily accessible. Another clinician described seeing patients in between specialty care appointments and making treatment adjustments, suggesting a need to co-manage patients due to difficulty accessing specialty care:

> It's so hard for them to get back in to [the mental health clinic to] make adjustments on their doses that they just give up and don't take [the medications] or they come back over here to me [in primary care]. [Patients tell me] 'I just tried to call and I can't get in with anybody.' (C7)

Patients identified other barriers to referral including lack of insurance coverage and associated financial cost of specialty care, and needing to travel to a second clinic location:

> Well, here lately I [don't have] insurance or nothing so I [haven't] been able to see them. I don't have the money to pay them. (P1)

Facilitators

Clinicians reported successfully referring patients to specialty care involved following up with the patient about the specialty referral. Additionally, clinicians (aware of the potential for patients to receive high quality of care in specialty care) maintained motivation to refer patients and described strategies to promote patients attending specialty appointments:

> We call them to see if the patients kept their appointment. (C2)

Patients reported few facilitators to referral but did reflect on past specialty care experiences:

> [The psychiatrist] diagnosed me and officially put me on mood stabilizers, things like that for bipolar. (P4)
> I was having a lot of problems at work and the bosses helped me get into a mental health facility. And I was going to them for years. (P2)

Theme 3: medication treatment

Barriers

Primary care clinicians reported concerns about initiating treatment when there was uncertainty in diagnosis, and how clinicians are usually more experienced with and prepared for diagnosing and treating patients with major depressive disorder rather than with bipolar disorder. When clinicians did describe prescribing medications to treat patients with bipolar disorder, some described using low or cautious dosing, or having experience and knowledge about using one mood-stabilizing medication only:

> [I prescribe] a little bit of [quetiapine], not a lot. That's about it. (C7)

Patients reported concerns about quality of care in primary care including having concerns about staying on ineffective medication treatment and wishing care could be more intensive in primary care or that clinicians could spend more time listening. Patients also described wanting access to psychosocial care such as psychotherapy or support groups and recognized that these services were usually not provided in primary care.

> [The doctors] just seem to rush in to get you in and get you out so they can get the next one in. (P5)
> They could improve their, like… they don't have anything around here. Really they don't have anything around here to setup for no kind of therapy or nothing like that. (P3)

Facilitators

Primary care clinicians reported risks associated with delaying treatment and at times wanted to start medication treatment for patients with bipolar disorder even after referring to specialty mental health care, or when referrals were not completed.

> I think maybe if they were started on treatment here instead of waiting maybe a month before they get another appointment and they're in a crisis. (C2)
> We're recognizing bipolar [disorder] a lot more, and actually doing something first line without waiting for the referral process. (C3)

Clinicians also described what they thought could help them care for patients with bipolar disorder in the future using local practice-based solutions. For example, clinicians described their ideas on how psychiatrists could support reaching an accurate diagnosis or treatment of patients with bipolar disorder in primary care such as through telepsychiatry consultation:

> A lot of times we just need some advice or some guidance on what to prescribe or what to add on. (C5)

Patients reported facilitators to medication treatment including easier access to appointments in primary compared with specialty care, opportunity for a consistent and longer-term relationship with primary care clinicians, and enhanced satisfaction with care in primary care when psychosocial needs could be met such as with the presence of a care manager.

Conclusions

We found that the themes of bipolar disorder detection, referral to specialty mental health care and medication treatment in primary care emerged from individual interviews with primary care patients and clinicians. The themes suggest primary care clinicians and patients face challenges detecting and then deciding whether to provide care that is easier to access, but less intensive, in primary care,

or referring the patient for specialty care that can be more intensive treatment but harder to access.

Primary care clinician uncertainty about diagnosis and when to proceed with treatment, combined with variability in access to specialist psychiatric consultations, can complicate clinical decision making. When faced with lack of local specialty care, clinicians in our study described expanding their scope to include evaluating for and treating patients with bipolar disorder. This finding is consistent with research on primary care clinicians' experiences evaluating and treating patients with other chronic but somewhat uncommon illnesses such as heart failure (28).

Patients and clinicians in our study described being able to access and prescribe medication treatment, but not other types of treatment, in primary care. Treatment guidelines recommend offering individuals with bipolar depression psychosocial interventions such as psychotherapy (29). A prior study found that primary care patients with serious mental illness including bipolar disorder reported expecting 'good enough' primary care including treatment with psychotropic medication and a consistent relationship with a primary care clinician who could access psychiatrists for advice as needed (30). Addressing gaps in psychosocial care of patients with bipolar disorder may be feasible in primary care settings and has been accomplished for treating individuals with other symptom domains. For example, primary care patients with depression and pain have reported concerns about inconsistent recommendations on psychosocial treatments from primary care clinicians (31); however, when provided, interventions involving medication and psychosocial treatments can reduce symptoms in both domains (32).

Despite ease of appointment access and opportunity for longer-term relationship, patients in our study reported some concern about not feeling listened to by clinicians, while clinicians viewed time during appointments with patients with bipolar disorder as being taken up by care of co-occurring chronic conditions. Optimizing care of patients with bipolar disorder in primary care would likely require evaluating appointment agenda and perhaps systematic assessment of bipolar disorder symptoms.

Consulting psychiatrists have reported believing it is feasible to adequately treat some patients with bipolar disorder in primary care (3,33). Psychiatry consultation may also be needed to provide effective care for patients with bipolar disorder in primary care, as others have found in studies on primary care clinicians' experiences with initiating treatment for patients with posttraumatic stress disorder (34). Participants in our study suggested the use of telehealth technology as one strategy to more easily access psychiatric experts, possibly due to the ACIP focusing on implementing telehealth solutions. Recent data on telehealth care in the USA revealed 30% of all telehealth claims in Medicaid were visits with a diagnosis code of bipolar disorder (35). These factors suggest that the focus of this ACIP, and stated preference of participants in our study, could reflect a trend of use of telehealth to care for some patients with bipolar disorder (36).

Limitations include the study being conducted with a convenience sample of clinicians and patients, all clinical sites being rural sites in one state, use of patient- or chart-reported diagnoses for included patients, and data collection occurred in 2012 preceding recent research on bipolar disorder in primary care. Clinicians included in our study were experienced clinicians with current leadership positions giving participants the opportunity to provide data on their personal and clinic-wide experiences. Lack of access to specialty care is common in rural sites and may have influenced the results of our study; though, epidemiologic data (18) from the USA have shown that in general a significant proportion of individuals with bipolar disorder do not access specialty mental health care.

Our study and related literature revealed challenges associated with accurately detecting individuals with bipolar spectrum disorders and initiating appropriate treatments, and the tension between treating in primary care versus referring to specialty care. Potential next steps in research include identifying ways to aid primary care clinicians in detection of patients with bipolar spectrum disorders, and strategies for treatment of patients in primary care with access to consultation and co-management with specialty care.

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