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Self-Identified Barriers to Rural Mental Health Services in Iowa by Patients with Multiple Comorbidities: A Qualitative Interview Study

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Self-Identified Barriers to Rural Mental Health Services in Iowa by Patients with Multiple

Comorbidities:

Qualitative Interview Study

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ABSTRACT

Objectives: Individuals in rural areas face critical health disparities, including limited access to mental healthcare services and elevated burden of chronic illnesses. While disease outcomes are often worse in individuals who have both physical and mental comorbidities, few studies have examined rural, chronically-ill patients' experiences accessing mental health services. While disease outcomes are often worse in individuals who have both physical and mental comorbidities, few studies have examined rural, chronically-ill patients' experiences accessing mental health services. The aim of the study was to determine barriers to finding, receiving, and adhering to mental health treatments in this population to inform future interventions delivering services.

Design: We conducted a qualitative study of barriers to mental healthcare access. Nineteen interviews were analyzed deductively for barriers using a modified version of Penchansky & Thomas's theory of access as an analytic framework.

Setting: This study was conducted remotely using telephonic interviews. Participants were located in various rural Iowa towns and cities.

Participants: 15 rural Iowans with multiple physical comorbidities as well as anxiety and/or depression.

Results: We found that while patients in this study often felt that their mental health was important to address, they experienced multiple, but overlapping, barriers to services that delayed care or broke their continuity of receiving care, including limited knowledge of extant services and how to find them, difficulties obtaining referrals, and unsatisfactory relationships with mental health service providers.

Conclusions: Our findings highlight the need for intervention across multiple domains of access is necessary for successful long-term management of mental health disorders for patients with multiple chronic comorbidities in Iowa.

STRENGTHS AND LIMITATIONS OF THE STUDY:

- This study used an adapted theory of access to demonstrate multiple pathways by which access to rural mental health services in Iowa was hindered.

- Qualitative findings highlight lived experiences and provided context for barriers experienced among an understudied population.

- This study is the first qualitative investigation, to our knowledge, of barriers experienced by rural Iowans after the privatization of Medicaid and the state-wide shift towards community-based mental health services, which changed the distribution and delivery of services compared to previous years.

- The main limitations of this study was that it used a small, largely homogenous population which may have limited generalizability; experiences of rural patients of color may not be represented in the study findings.

INTRODUCTION

Mental illness is one of the largest contributors to disease and disability in the US. [1] [2] Despite this, access and delivery of mental healthcare services in rural settings remains a critical public health issue. Rural residents are less likely to seek and receive treatment for their mental health than those living in urban areas. [3] Further, rural individuals being treated for their mental health have fewer mental health visits and are less likely to see a specialist for their mental health than their urban counterparts. [4] Stigma, lack of mental health care specialists, and an overall insufficient healthcare workforce have been frequently cited as common barriers to delivering mental health services to rural populations. [4-9]

In addition to disparities in mental health services, rural populations are also disproportionately affected by chronic diseases. Conditions such as cardiovascular disease, stroke, and diabetes often have higher prevalence and have worse outcomes in the presence of mental health disorders. [10-15] In fact, the greater the severity of mental illness, the higher the incidence and excess mortality from many chronic illnesses, such as cardiovascular and respiratory diseases. [16] Since comorbid mental illness has been demonstrated to shorten lifespans in the presence of physical morbidities, [17] unmet mental health needs may be an underlying factor contributing to this excess mortality in rural areas.

Given that rurality and chronic illness often share multiple and reciprocal pathways for poor mental health, [15] [18-21] it is worth investigating rural chronically-ill patients' engagement with mental health care. However, there is a paucity of research on the experiences of patients in rural areas regarding their use of mental health care, and it is unknown if chronically-ill rural patients have unique or excess barriers to mental health care than those without chronic illnesses.

In this paper we describe patient-reported barriers to seeking, receiving, and adhering to

mental health treatments in rural Iowans with multiple physical comorbidities. We used a

modified version of Penchansky & Thomas's theory of access [22] to characterize barriers reported

by patients during semi-structured interviews. Using this adapted model, we were able to

characterize barriers across six dimensions of access for this patient population. The information

from this study was intended to identify areas for intervention to expand access to mental health

services in this high-risk, but underserved population.

Defining access

Access to healthcare is a central problem to healthcare service provision and is one of the

most widely used concepts in discussions about healthcare policy. The concept of "access"

encompasses multiple dimensions and pathways that enable users to find, enter, and utilize

healthcare systems. Access is often defined in the literature as the degree to which characteristics

of the healthcare system fit the characteristics of the health system users, [22] although these

dimensions have been defined differently by different authors. [23] [24]

In 1981, Penchansky & Thomas developed a theory of access which is still widely used

to conceptualize problems of access in public health research. The theory contained five

dimensions: availability (supply and demand of services), accessibility (location of supply to

patients), accommodation (organization of system to accept patients), affordability (price of

services and patients' ability to pay for services), and acceptability (patient attitudes about the

immutability qualities about the service and service provider, and vise-versa). [22]

Noting that the original theory did not account for patient knowledge and understanding

of extant services, Levesque's split model of access, which describes parallel user and system

dimensions of access, posits that the "ability to perceive" a need for care is critical to healthcare access. [24] Similarly, Saurman added a sixth dimension of access— awareness—to Penchansky & Thomas's theory after an evaluation of a telepsychiatry program revealed that many users of emergency mental health services were unaware of the existence of these services, what they entailed, and who they were intended to serve. [23]

In the previous decade, there were calls for policy to increase intervention on select dimensions of access from Penchansky & Thomas's model. For instance, the 2015 National Rural Health Association (NRHA) released a policy brief calling for a "multi-pronged approach" to mental health disparities through focusing on disparities of availability, accessibility, affordability, and acceptability. [25] Similarly, Smalley and colleagues identified three key areas— accessibility, availability, and acceptability— to decrease rural mental health disparities. [26] While these calls correctly identified a need to address multiple pathways contributing to disparities in mental healthcare access, they disregard other important dimensions of access. Further, while these provide helpful models for conceptualizing access, there are few studies grounding the utility of these theories in empirical investigations of patient experiences. Rural patients with multiple comorbidities are particularly interesting to study, as they paradoxically have relatively high contact with medical professionals, but still face disparities in mental health care access.

METHODS

Context and setting

To fill this gap, we conducted a qualitative study of barriers and facilitators to rurally-based mental health care. We collected semi-structured interviews over the phone and analyzed them by applying a modified Penchansky & Thomas's theory of access as an analytical

framework. A sample of rurally-based patients with multiple chronic physical comorbidities and

anxiety and/or depression were enrolled from a previous prospective, cluster-randomized,

controlled clinical trial called Improved Cardiovascular Risk Reduction to Enhance Rural

Primary Care, or ICARE. [27] [28] ICARE was conducted in 12 private physician offices in Iowa. All

the study procedures for both ICARE and this study were approved by the university Institutional

Review Board prior to beginning research activities.

Overall study design:

This is a qualitative study of semi-structured interviews. We used a prior study (ICARE)

as a convenience sample. Interviews were conducted over the phone and analyzed deductively in

NVIVO. [29]

Eligibility:

This study used patients from the original ICARE study as a convenience sample of

chronically-ill patients receiving rurally-based mental health care. The original ICARE study

followed a two-step process for inclusion.[28] First, English-speaking males and females aged 50 or

older who were seen at their primary care clinic within the previous 24 months with at least one of

the following conditions were identified: 1) diabetes 2) hypertension, or 3) hypercholesterolemia

with a history of peripheral artery disease, coronary artery disease, stroke, transient ischemic

attack, or diabetes. Second, subjects had to have at least three chronic illnesses or risk factors that

could include the aforementioned diseases or any of the following: coronary artery disease,

myocardial infarction, stroke, transient ischemic attack, atrial fibrillation, peripheral vascular

disease, claudication, carotid artery disease, current smoking, or obesity.

ICARE patients were eligible to participate in the present study if they 1) self-reported

ever having a diagnosis of anxiety or depression or 2) had a diagnosis of anxiety or depression

reported in their electronic medical records, which was determined during the ICARE trial. The justification for examining mental health in ICARE patients stemmed from a finding that anxiety and depression were highly prevalent in this cohort, as 156 of the 302 patients enrolled in the ICARE study had self-reported or diagnosed anxiety or depression during the trial, indicating the potential for unmet care needs and elevated cardiovascular risk. [27]

Recruitment

We contacted 156 eligible patients through mailed letters containing the elements of informed consent. Interested patients then notified us of their willingness to participate by returning a postcard with their contact information, contacting us via a dedicated study phone number, or the study email address. Twelve ICARE patients could not be contacted due to changes in address made since the clinical trial ended. The first author then contacted the patient to schedule a time for an interview over the phone. Patients could be contacted up to three times to schedule an initial interview before being lost to follow-up. Patients could be interviewed up to two additional times to clarify questions that arose during the analysis process. Patients were offered a $25 check voucher for every interview completed.

Data collection

Interviews were conducted from September 2017 – June 2018 by the first author. A semi-structured interview guide was developed by the first and second authors and contained questions about the patient's past and current experiences obtaining mental healthcare and with different treatments, how they discussed their mental health with providers, their knowledge of available resources, how they prioritized and balanced their mental and physical healthcare needs, and what ideally their mental healthcare would include. The interview guide underwent iterative revisions by the first and second authors by reviewing interview audio and transcripts

throughout the data collection process and adding or changing questions to probe for additional or missing information. Interviews lasted between 20 minutes to 2 hours and were recorded. To protect patient privacy, identifying information was redacted from audio files using Audacity. Audio files were transcribed using an online transcription service (Rev.com).

Data analysis

Analysis of qualitative data was performed by deductive thematic analysis using a modified theory of access described by Penchansky & Thomas and Saurman. The first and second authors developed a codebook that contained six broad dimensions of access previously described in the literature as categories for analysis—accessibility, availability, affordability, accommodation, acceptability, and awareness. Conflicts about coding were resolved among the research team by discussing and revising the codebook. The final codebook was developed by two researchers coding two (~10%) transcripts independently and comparing results for agreement.

Transcripts were then coded deductively line-by-line using NVIVO [29] for barriers and facilitators for access to mental healthcare by the first author. For the purposes of analysis, we used a broad definition of mental health services, including specialized care, primary care, and more informal care settings, such as support groups. Text was coded as a facilitator if it assisted the patient in receiving or adhering to mental health treatment. Conversely, text was coded as a barrier if it prevented the patient from receiving or sustaining mental healthcare. When all transcripts were coded, the coded text within each category was compared for similarities endorsed by patients across interviews. Similarities within our analytic categories were grouped into themes. Themes with illustrative quotations are described in the results section.

Patient and public involvement:

Participants were not involved in any phase of the development, design, or writing of this study.

RESULTS

Nineteen prospective subjects contacted us with their interest in participating; 3 were lost to follow-up and 1 decided not to be interviewed. We ultimately interviewed 15 patients. Four patients were re-interviewed for follow-up questions, resulting in a total of 19 interviews. The majority of patients were female, white, and had an educational attainment of 12 years or fewer (Table 1). Nearly three-quarters of patients had public insurance. We recruited ICARE patients with either diagnosed or self-reported anxiety and/or depression; however, when asked if they had ever received a mental health diagnosis, patients also reported: post-traumatic stress disorder (PTSD), panic disorder, bipolar-II, substance abuse, "anger issues," and prior suicidality. Patients rated both their physical and mental health as important health priorities.

Table 1: Patient characteristics (n= 15)

Variable	Mean (SD)	N (%)
Age (range 53-71 years)	61.7 (5.1)	
Gender		
Female		12 (80)
Male		3 (20)
Race & ethnicity		
White, non-Hispanic		14 (93.33)
Black		1 (6.67)
Educational attainment		
≤ 12 years		9 (60)
Associates or technical degree		4 (26.67)
College or higher		2 (13.33)
Insurance type		
Medicare		7 (46.67)
Medicaid		4 (26.67)
Private		3 (20)
None/self-pay		1 (6.67)
ICARE recruitment criteria		
Diagnosis of depression		9 (60)
Diagnosis of anxiety		9 (60)
Self-reported depression		10 (66.67)
Self-reported anxiety		12 (80)
Ever had a mental health diagnosis		11 (73.3)
Ever took psychiatric medication		13 (86.67)
Currently taking psychiatric medication		12 (80)
Ever saw a mental health specialist		13 (86.67)
Psychiatrist		6 (46.15)
Psychiatric nurse		1 (7.69)
Therapist or counselor		10 (76.92)
Currently seeing a mental health specialist		4 (26.67)
Psychiatrist		2 (13.33)
Therapist or counselor		2 (13.33)
Self-rated importance of addressing mental health (1= least important, 10= most important)	8.93 (1.73)	
Self-rated importance of addressing physical health (1= least important, 10=most important)	9.46 (.88)	

A requirement of enrolling in the ICARE study was that all patients had a primary care provider, thus, in this sub-study all patients had some level of access to medical care. Most patients were receiving mental health services through their primary care providers. A majority of patients had seen mental health specialists (either a psychiatrist, psychiatric nurse, or a therapist) at some point in their lifetime. However, only slightly more than a quarter were currently seeing a provider other than their PCP for their mental health. Despite this current level of access, patients reported a myriad of barriers to mental health care in rural settings, which are summarized in Table 2 and described below.

Table 2: Dimensions of access and patient-reported barriers to mental health care

Dimensions	Definition	Patient-reported Barriers
Accessibility	Services are offered within a reasonable proximity to patient in terms of time and distance.	- Distance to mental health specialists/resources - Lack of motility - Severe chronic illness
Availability	Services physically exist, are in adequate supply, and can meet the volume and needs of the patients served.	- Difficulty establishing long-term relationships with providers - Lack of facilities offering mental health services
Affordability	Cost to consumer and the financial viability of service provider. Includes payment from multiple funding streams.	- Lack of mental health parity - Pharmaceuticals not covered - Out-of-pocket cost
Accommodation	Clinic operations are organized such that patients can utilize services easily; services are easy and convenient to obtain and use.	- Communication channel incompatible with patient - Waiting lists/waiting times - Crisis care unavailable - Difficulty receiving referrals
Acceptability	Patient attitudes about the personal and practice characteristics of a provider or qualities of a healthcare service.	- Relationship and communication with provider - Treatment incompatible with patient
Awareness	Patients can identify that some form of services exist, can be reached, and have an impact on the health of the individual.	- Inability to locate resources - Poor health literacy - Poor knowledge of mental health system

Accessibility

Accessibility refers to the relationship between patients, the location of services, and the time spent traveling to obtain them. Patients indicated differences in accessibility for PCPs and mental health professionals, such as therapists and psychiatrists. Most patients reported that their PCP practiced locally and was easier to access in terms of time and distance; thus, for many, their PCP was the most accessible provider for obtaining mental health services. Patients faced more difficulty traveling to psychiatrists, therapists, and support groups due to distance and time spent traveling. Patients frequently estimated traveling times of a minimum of 45 minutes to the next largest town that would offer specialist resources. Some patients noted that while some form of specialist resources might be available locally, they felt that other places had better resources than what was immediately available. One respondent stated:

> The bottom line is if you need help, you can get it, but the degree
>
> of expertise that lies in these people is not like a big city. This is a
>
> different caliber of doctor. (Patient 3, M, aged 62)

Further, transportation was also a barrier for rural and chronically ill patients. Some patients reported a lack of mobility or independence for traveling, such as not having a driver's license, broken vehicles, or being mostly house-bound from severe chronic illness, such as cancers and chronic pain; these patients relied on friends and family to help them get to medical appointments.

Availability

Availability refers to the relationship between quantity and quality of services and patient demand for services. Patients reported many factors that impacted the availability of mental

health services. During the course of the ICARE study, and prior to these interviews, the

governor privatized Medicaid and also closed several mental health facilities in Iowa. Notably,

several patients discussed the closure of state-run mental health facilities and psychiatric units as

an indication of dwindling resources or opportunities for receiving mental healthcare, even

though none had disclosed having been patients at those facilities. These closures gave some

patients the perception that mental health services were overall in short supply. As one patient

stated:

> In our town it seems like people can't get help. They'll end up
>
> going to jail and the jail tries pushing them off onto mental health
>
> or vice versa. There should be a place that they can go, but every
>
> time you turn around they're wanting to close them. … Doctors are
>
> doing okay as far as I'm concerned in this town, but it's their
>
> limited resources. (Patient 13, F, aged 60)

In addition to a shortage of physical facilities, patients often noted a lack of providers,

particularly those with specialist expertise. Patients who were currently receiving specialized

mental health care noted that their providers had high patient loads and it was difficult to get an

appointment with a specialist provider, particularly psychiatrists. Again, PCPs were often easier

to see when problems arose:

> My psychiatrist is a little difficult because there are so many
>
> people at [clinic], mental health runs rampant over there. My
>
> doctor's appointments are easier. I called on Friday, had an
>
> appointment Monday. (Patient 10, F, aged 67)

Affordability

Affordability refers to the ability for healthcare services to be reimbursed through

different funding streams. While all patients in this study had some access to physical and mental

healthcare in terms of paying for services, the ability to pay for services was dependent on the

type of provider and degree of insurance coverage. While receiving some types of mental health

care from PCPs was often a more affordable option, receiving specialist services was less

frequently affordable, with patients reporting paying high copays for clinic visits and

medications. Some patients were retired or did not earn enough to cover copays. Insurance

coverage was particularly problematic for patients seeking therapists:

> I could always go to a psychologist, but it costs money. I live on a
>
> fixed income with Social Security. I don't have extra money that I
>
> could just say, "Gee, I think I'll make an appointment with a
>
> therapist." (Patient 10, F, aged 67)

Patients in this sample were largely insured through Medicare and Medicaid (~73%),

which had limitations due to the low number of mental health professionals accepting subsidized

insurance. The recent changes in Iowa's privatized Medicaid system left some patients with gaps

in their mental healthcare coverage after one managed care organization dropped out of the

program, which in turn impacted the availability of treatment options. For instance, one patient

recalled recently being forced to cancel appointments with his therapist after the change. Another

patient recalled that insurance companies were not willing to cover more expensive depression

medications prescribed by her physician:

> Now we are living by what the insurance companies tell us. And I
>
> suppose that even includes the depression type drugs… They
>
> won't pay for it. 90% of the time it seems that insurance

companies are rejecting what the doctor says. Get to the pharmacy

and you have to play "find out what we can do for you." (Patient 1,

F, aged 63)

Accommodation

Accommodation refers to the ease and convenience of using services. Patients described

several ways that extant services were made less accessible due to organizational and policy

factors within primary care and mental health clinics.

First, communication with the patient influenced adherence and appointment attendance.

Clinics did not always communicate to the patient through their preferred channels, meaning that

reminders about upcoming appointments and important updates about the patients' care were

sometimes missed. In the context of mental health services, the lack of communication between

patients and providers could be disruptive to their care. This is exemplified by one patient's

account how her clinic did not notified her about her mental health provider leaving:

I was devastated because my lady that I go see just up and left.

And I'd been seeing her for 10 or 15 years. She went to a different

job down thirty miles from here. I started crying right there. She let

people know a month in advance, but I was seeing her every six

weeks. So needless to say I did not see anybody. (Patient 13, F,

aged 60)

Further, clinical protocols such as depression or anxiety screening may influence how

readily patients initiate or alter aspects of their mental healthcare. For instance, some patients

receiving mental health services through their PCP said their physician never asked them about

their emotional well-being and had only begun treatment after telling their physicians that they

suspected they had depression; these patients felt responsible for initiating discussions about

their mood and treatment outcomes. However, not all patients were willing to initiate these

conversations unprompted. As one patient suggested:

> Every time I go to see [my doctor], he asks me if I'm depressed.
>
> But I don't know that every doctor does that. I think that mental
>
> health sometimes is overlooked, but sometimes it's the root of
>
> some of your physical problems. So I think the doctors need to
>
> approach it as my doctor does and ask me how I'm doing mentally.
>
> (Patient 9, F, aged 72)

Referral policies and procedures also impacted the ability of patients to receive

specialized mental healthcare. Many patients were uncertain about where to receive additional or

specialized services and relied on their PCPs for referrals. However, some patients had trouble

requesting and receiving referrals to other providers or resources. This became a significant

barrier when patients needed services beyond what their PCP could provide:

> I know my doctor never suggested talking to anybody or doing
>
> anything more, and you can't hardly get referrals to go see other
>
> people without the doctors. … You almost always have to have
>
> that referral. And then its question is who's good and who's not
>
> good, and I don't know how to figure that part out. (Patient 1, F,
>
> aged 63)

Patient 1 ultimately never received a referral but decided to stay with her PCP due to her

proximity to the clinic. Even after finding specialized care, other patients found that it was

difficult to initiate services with new providers for different reasons. Some facilities were not

accepting new patients or were not willing to allow clients to see other therapists within their

facility when patients requested a change. These problems then prompted patients to cease care

with that provider in favor of seeking a more accommodating one, as exemplified by this patient

who had requested to see a different therapist:

By the end of five months, I asked to see someone else. They told

me that they don't do that. So I never went back. (Patient 10, F,

aged 67)

Acceptability

Acceptability refers to patient attitudes about the characteristics of a provider or a

healthcare service and vise-versa. In other words, acceptability describes the degree to which

patients and providers tolerate the immutable qualities of one another or the service being

offered. In this sample, the most significant patient-reported barriers impacting acceptability

were poor relationships with the provider and dissatisfaction with aspects of the treatment.

Patients described the relationship they had with any mental healthcare provider as one of

the most significant determinants of whether they would continue seeking mental healthcare

care. A negative experience with a mental health provider could prevent the patient from

returning for subsequent visits. Sometimes this resulted in a further delay for seeking treatment

with other providers for long periods of time ranging from months to years:

I saw that therapist I think in 2010. Didn't work for me. I just didn't

feel like I was talking to somebody who understood what I was

going through. That's really difficult for me. Most of the time I

never finished the sessions. (Patient 10, F, aged 67)

At the time of the interview in 2018, this patient had experienced a recent increase in her

anxiety. Only when a provider she trusted, her long-term psychiatrist, suggested that she talk to a

therapist did she reluctantly consider going again, stating, "I'm going to try it again. I'm very

hesitant about doing it."

Notably, patients overall did not feel that providers' professional backgrounds (such as

psychiatry or family medicine) were as important as their interpersonal skills. When asked about

what they were looking for in a mental health provider, patients described the ideal provider as

someone who was trustworthy; regardless of their professional background, providers should be

comfortable discussing mental health concerns and patient histories, understanding of their

feelings and preferences, and be an active, empathetic listener. Patients valued being able to

communicate openly about their experiences without fear of judgement. Patients felt that being

truly heard and understood was paramount to their own recoveries:

I've noticed that some doctors are kind of like "Oh, I don't wanna

talk about that."... If you're gonna shy away from this, what else

are you gonna shy away from? So I didn't feel comfortable with

them, and I was like "Forget it". … You've gotta be able to talk to

them about mental health, your physical health. (Patient 11, F,

aged 54)

Several patients reported having prior negative experiences with a provider that they saw

for their mental health. Thus, patients were eager to retain providers they liked for as long as

needed. Patients felt that having a positive long-term relationship with a provider enabled them

to receive better mental healthcare, as it enabled their provider to interpret their affect accurately:

> I think from all the times that I've went and seen her that she knew
>
> that something's wrong even if I didn't want to tell her about it.
>
> And I think that, to me that showed me that she really cared. That
>
> she knew my thoughts and feelings. (Patient 13, F, aged 60)

Patients also discussed disruption of valued clinical relationships as significant barriers to

receiving mental health care; the impact of providers leaving their clinics often meant that the

patient would have to start looking for trusted providers again. Sometimes this left a gap in the

management or provision of their mental health care for several months. Since patients in this

sample preferred to stay with the same trusted provider, disruptions in clinical relationships were

often emotional experiences, as it was for one patient whose long-term PCP, who also managed

her depression and anxiety treatment at the time, retired:

> I was so upset. I told him, "I'm not happy about this," when he let
>
> us know. We got a letter and I just felt like crying because I did not
>
> want that to ever happen. I always thought "I'll have him forever."
>
> (Patient 8, F, aged 70)

Additionally, patients valued being able to collaborate with their providers on treatment

decisions. Some patients felt that their previous providers didn't respect their desire to alter

aspects about their treatment or therapy, which lead to them ceasing care with that provider. This

seemed especially true for patients who wished to discontinue medications with deleterious side-

effects:

> Well, I had told [psychiatrist] my prior experience with certain
>
> drugs. … And he was coming up with these diagnoses that really
>
> were not pertinent to me. He knew it all, you know. … I already
>
> told him that I don't take those drugs and that I've tried them in the
>
> past and they just haven't worked for me. We didn't have a very
>
> good connection. (Patient 3, M, aged 62)

While patients said they were generally open-minded about their providers'

recommendations, they framed providers' willingness to negotiate treatment options to find the

best fit as an indication that their providers truly understood their needs. As the previous patient

stated:

> If they're willing to meet me halfway, we get along just fine. But
>
> just don't talk. You also have to listen. A lot of doctors don't
>
> wanna listen. You throw up a couple of symptoms, this and that,
>
> they've already got a diagnosis. But they really don't know your
>
> history. … That's why I wouldn't want to lose the doctor I have
>
> right now. (Patient 3, M, aged 62)

Finally, patients described different ways that their treatment options were not compatible

with patients in terms with their clinical or personal goals. Many patients recounted at least one

time they had been dissatisfied with their psychiatric medication. However, sometimes patients

felt that medication was not right for them, and sought other services, such as counseling or

therapy, but also encountered difficulties finding or asking for alternatives:

> There was a point when I got so depressed, and all the doctor
>
> wanted to do was give me pills. Beyond that, they weren't too

> interested. So you take the pills, you sleep a lot…you really don't
>
> get any better. … They may help, but it won't get to the problems,
>
> of how to really deal with the way you're feeling and things. … I
>
> just felt kind of let down…you know, when I did get to the point
>
> where I asked for [help], it wasn't like it was a high on her list. She
>
> gave a prescription but that's not it. (Patient 1, F, aged 63)

Awareness

Awareness refers to patients' ability to perceive and locate extant services, as well as their health literacy. In other words, patients can identify that some form of services exist, can be reached, and have an impact on the health of the individual. Overall, patients said they were largely uncertain about where to go for mental health concerns and were less familiar with extant options for receiving mental health services than their physical health care.

Patients had varying knowledge of Iowa's mental health system and mental healthcare options. For instance, most patients who had received some form of services from a mental health specialist, such as a psychiatrist or therapist, could not describe how different treatment options worked. Further, some patients could not readily distinguish between different provider types, including their own service providers, and were unsure of how to access services offered by different provider types. While PCPs were more accessible and available than other provider types, not all patients were aware that they could or should discuss mental health concerns with their PCP, as one patient put it:

> Usually if you're going to the doctor you may quiz them about
>
> some other things. But it's not like I make an appointment just to

> go and discuss mental. I go in to do my *medical* stuff and discuss
>
> it. (Patient 1, F, aged 63, emphasis in original)

Another reported barrier that resulted in delaying seeking treatment was an initial lack of knowledge about common mental health disorders. Patients in the sample usually described learning about mental health conditions and services only after experiencing them first-hand. For instance, many patients reported that they first learned about anxiety or depression after they had been diagnosed with the condition. In some cases, patients learned about these conditions from family and friends with similar experiences, who then told them how to seek care.

Patients differed in their abilities and preferred channels for finding out information about their conditions, local resources, and treatment options. While patients primarily could only name the places that they had previously received services, over the course of the interviews they mentioned several preferred channels for researching other options, including the local phonebook or service directory, magazines, and local churches. While one patient said they would research their options on the internet, two others said they were unable to use internet searches to find more information (one didn't have a computer, the other didn't know how to search). Many patients felt that extant mental health services were not apparent to those in need. As one patient stated:

> Some [mental health services] don't advertise, so a lot of people
>
> don't know … what's available. You see all these other
>
> advertisements, but you never see where to go for mental health
>
> help. Not once have I seen help for that. So I don't think people
>
> know where to turn. (Patient 11, F, aged 54)

Facilitating awareness, PCPs emerged as one of the most important sources for education

and information for patients, as patients reported relying heavily or even solely on their PCPs for

information about mental health conditions. When asked where they would go if they had

questions or developed new problems with their mental health, most patients said they would

return to their PCP. As one patient stated in her advice to patients going through similar struggles

with their mental health, one patient responded:

> Go to their family doctor and tell them exactly what they're
>
> feeling. It's the only way that they can get any guidance. (Patient 8,
>
> F, aged 70)

DISCUSSION

This study examined barriers experienced by a sample of 15 rural adults managing

multiple physical conditions as well as depression and/or anxiety. We found that while patients

in the study generally believed that treating both their physical and mental health were important

priorities, long-term mental healthcare with any one provider was often hindered by multiple,

sometimes over-lapping barriers. Except for the dimension of accessibility, we did not observe

chronic illness contributing to excess barriers to receiving mental health services among our

sample. Despite this, most patients experienced at least one barrier to receiving mental healthcare

in their lifetimes. This study is the first qualitative investigation, to our knowledge, of barriers

experienced by rural Iowans after the privatization of Medicaid and the state-wide shift towards

community-based mental health services, which changed the distribution and delivery of services

compared to previous years. This study contributes to our understanding of the impact of this

changing context for delivering rural mental health services.

While studies about rural US adults with comorbid physical and mental comorbidities are particularly limited, findings from this study both confirm and augment those of extant research on rural health disparities. For example, the importance of a good patient-doctor relationship has been found in previous studies [30] and may be more important than other factors, such as distance to services, for rural patients. [31] The present study suggests that shared decision-making between the patient and provider, as well as clinical organization, may facilitate positive patient-physician relationships and greater adherence to treatment. Further, similar to Saurman *et al*, we found that patients' awareness of extant mental health services was indeed a critical dimension of access in rural populations; [23 32] our findings indicate rural social networks and public advertisement of mental health services in clinics or in the community may be viable avenues for promoting service utilization by facilitating awareness. While strengthening the role of the PCP in managing common psychiatric concerns, such as anxiety and depression, has been proposed as an intervention to improving access in rural areas, [33] our results complicate that strategy, as patients in our study felt that PCPs, while the most accessible, were not always the most acceptable option for addressing their mental health concerns. Finally, while other studies of mental health service utilization by rural individuals demonstrate how stigma affects the acceptability of services, [34] our study finds that other issues, such as feeling understood by the provider, impact the acceptability of services, even among patients who actively want help.

Our study has important implications for intervention planning. As reported by the study's patients, barriers to access were often related to one another. For instance, under accessibility, patients reported unreliable transportation arrangements or mobility issues that made traveling more difficult than other rural individuals. Similarly, under the dimension of availability, patients felt they had few local options and would have to travel to find care.

Finding diverse means to deliver mental health services either locally or remotely may be especially important for rural individuals with limited mobility. Similarly, the patient-provider relationship was a significant finding in both the dimensions of availability (difficulty establishing clinical relationships) and acceptability (relationship and communication with provider), and strongly influenced patients' desire to return for appointments. Finally, awareness was pertinent to both the dimensions of availability and acceptability, as it influenced patients' knowledge of how to seek mental healthcare, as well as shaped patients' expectations of clinical outcomes. These results indicate that interventions aimed at this population should account for multiple barriers to access.

This study had several limitations. First, patients in this study were largely female and nearly exclusively white. This may reflect the gender and race differences in help-seeking patterns, which has been well-documented in other studies [35]. Further, the barriers to access experienced by Iowans of color may not be represented in these findings, indicating a need to research the experiences of racial minorities obtaining rural mental healthcare, specifically. Second, while small sample sizes are appropriate for qualitative work, we only recruited ~12% and ultimately interviewed ~9% of eligible ICARE patients. This low-response rate may be a product of stigma against mental health disorders.

This study also had a number of strengths. We believe that our recruitment strategy using a convenience sample of rural patients from the ICARE study allowed us to interview in-depth patients from a number of towns across rural Iowa, thus allowing us to have a wide geographic sampling within the state and within multiple hospital and clinic systems. Further, our semi-structured and iterative approach to writing an interview guide allowed us flexibility to probe for issues that were important to participants. Finally, our analytic framework of a modified theory

of access from Penchansky & Thomas allowed us to account for and characterize multiple

interrelated barriers at once.

CONCLUSION:

This study offers important insight into the real-life experiences of rural individuals with

multiple comorbidities with seeking mental healthcare, such as the importance of the patient-

provider relationship in care-seeking behaviors, understanding of the diversity of healthcare

settings and provider types, and critical organizational and policy-level barriers. It is important

that interventions are grounded in the needs of intended service users; in this case, interventions

targeting rural individuals with multiple comorbidities may need to account for multiple and

overlapping barriers.

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FOOTNOTES:

Conflictions of interest: Authors report no conflicts of interest.

Author contributions: LP and KAK conceived and designed the study. BLC was the principal

investigator who designed and conducted the original ICARE study from which this sample was

obtained. LP and KAK participated in the recruitment of the subjects for this sub-study. LP and

KAK participated in the collection, analysis, and interpretation of data. LP drafted the

manuscript. KAK and BLC critically reviewed and approved this manuscript for publication.

Patient consent: obtained

IRB approval: Ethical approval for study activities was obtained from the University of Iowa

IRB (08/28/2017).

APPENDIX A: Phone script

Hello, my name is [NAME], and I am a Co-Investigator for the ICARE study you and your clinic participated in. As part of the study, a clinical pharmacist from the University of Iowa collaborated with clinic physicians in order to improve health outcomes for patients. We now hope to conduct an interview over the phone with 3-4 patients from that clinic so we can identify ways to improve mental health services in rural care settings. I received [an email or a postcard] indicating that you may be interested in participating in this interview over the telephone. The interview will take about 30-60 minutes. You also may be asked to participate in a follow-up 30-minute interview for clarification of questions that arise during the analysis of interview data. If you are interested in participating in a follow-up phone interview, you will be asked to leave a phone number and best time of day for phone contact.

Participation in this interview is completely voluntary. Is this interview something you may be interested participating in?

> *{If YES}* Do you have some time to do the interview now? Or we could set up a later time to do the interview if you don't have time now or wanted more time to think about participating.

> *{If NO}* I thank you for your time. Have a good day.

Let me go over some things before we begin.

If you have any questions, please feel free to ask me. Also, if you don't want to answer any questions just let me know.

With your permission, we will be recording this interview to ensure we accurately record what you say and so we can review your responses.

All information will be kept strictly confidential. I will use a random study ID number to identify you once we start recording.

Do you have any questions for me before we begin?

OK, I will begin recording now.

Hi, this is *[NAME]*. I am speaking with participant #_____.

Today's date is _____.

Thinking back on your interactions in health care clinics, please answer the following questions.

[interview questions]

APPENDIX B: Example interview questions

Interview guides were developed iteratively to probe for missing information.

Questions about patient's mental health service utilization

1. Have you ever been diagnosed with anxiety or depression?
2. Do you recall a provider ever asking you about your [anxiety/depression/mental health]? What about your mood?
    a. *{IF YES}*
        i. How did he or she ask?
        ii. When go to visit your healthcare provider, how often does he/she ask you about it? Every visit? Every few visits?
3. How is easy for you to talk about [anxiety/depression/mental health] with your provider?
4. Think about how your provider addresses your healthcare needs. Do you feel your provider thinks [anxiety/depression] is important to address?
    a. {IF PATIENT HAS DX}
        i. Do you think they spend enough time addressing your [anxiety/depression]?
5. Are you currently receiving any kind of treatment or therapy for [anxiety/depression] or any other mental health or mood issue?
    a. *{IF YES}*
        i. How satisfied are you with your current treatment?
        ii. Are there things you wish your provider would do differently regarding your mental health care?
            1. *{IF NO}*
                a. What do you like about their approach?
    b. *{IF NO}*
        i. Have you in the past?
6. Was there a time you needed care for [anxiety/depression] symptoms but could not or did not receive any?
    a. *{IF YES}*
        i. What would have helped you during that time?
7. Overall, what do you think would improve treatment of anxiety/depression for people experiencing it?

Healthcare priorities

8. Think about your healthcare needs and priorities. On a scale of 1-10, how important or urgent is treating your [anxiety/depression]?
        i. Why did you pick that numbers verses a [higher/lower] number?

ii. On a scale of 1-10, how important or urgent is treating your physical healthcare?

9. Do you have other health issues that trouble you a lot?
  b. *{If YES}*
      i. How do you balance those with addressing your mental health?

Patient preferences/conclusion:

10. In an ideal world, what would you look for in a mental health provider?
11. What would help you manage your [anxiety/depression] the most?
12. If you needed help with your mental health, who would you like to call?
13. Where would someone in your area go if they wanted help for their mental health?
14. Do you have any advice for patients struggling with a mood disorder?
15. Finally, do you have any recommendations for providers treating patients for [anxiety/depression/mood disorders]?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

BMJ Open

Self-Identified Barriers to Rural Mental Health Services in Iowa by Older Adults with Multiple Comorbidities: Qualitative Interview Study

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Access to Rural Mental Health Services   1

1 Self-Identified Barriers to Rural Mental Health Services in Iowa by Older Adults with Multiple

2   Comorbidities:

3   Qualitative Interview Study

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1 **ABSTRACT**

2 **Objectives**: Individuals in rural areas face critical health disparities, including limited access to

3 mental healthcare services and elevated burden of chronic illnesses. While disease outcomes are

4 often worse in individuals who have both physical and mental comorbidities, few studies have

5 examined rural, chronically-ill older adults' experiences accessing mental health services. The

6 aim of the study was to determine barriers to finding, receiving, and adhering to mental health

7 treatments in this population to inform future interventions delivering services.

8 **Design**: We conducted a qualitative study of barriers and facilitators to mental healthcare access.

9 19 interviews were analyzed deductively for barriers using a modified version of Penchansky

10 and Thomas's theory of access as an analytic framework.

11 **Setting**: This study was conducted remotely using telephonic interviews. Patients were located in

12 various rural Iowa towns and cities.

13 **Participants**: 15 rural Iowan older adults with multiple physical comorbidities as well as anxiety

14 and/or depression.

15 **Results**: We found that while patients in this study often felt that their mental health was

16 important to address, they experienced multiple, but overlapping, barriers to services that

17 delayed care or broke their continuity of receiving care, including limited knowledge of extant

18 services and how to find them, difficulties obtaining referrals, and unsatisfactory relationships

19 with mental health service providers.

20 **Conclusions**: Our findings indicate that intervention across multiple domains of access is

21 necessary for successful long-term management of mental health disorders for patients with

22 multiple chronic comorbidities in Iowa.

1 **STRENGTHS AND LIMITATIONS OF THE STUDY:**

2 - This study used an adapted theory of access to demonstrate multiple pathways by which

3 access to rural mental health services in Iowa was hindered.

4 - Participants were asked about their lived experiences and barriers encountered in seeking

5 mental healthcare in rural settings.

6 - This study is the first qualitative investigation, to our knowledge, of barriers experienced

7 by older rural Iowans after the privatization of Medicaid and the state-wide shift towards

8 community-based mental health services, which changed the distribution and delivery of

9 services compared to previous years.

10 - The main limitations of this study was that it used a small, largely homogenous

11 population which may have limited generalizability and possible selection bias;

12 experiences of rural patients of other racial and ethnic backgrounds may not be

13 represented in the study findings.

1 **INTRODUCTION**

2   Mental illness is one of the largest contributors to disease and disability in the United

3 States (US). [1] [2] Despite this, access and delivery of mental healthcare services in rural settings

4 remains a critical public health issue. Rural residents are less likely to seek and receive treatment

5 for their mental health than those living in urban areas. [3] Further, rural individuals being treated

6 for their mental health have fewer mental health visits and are less likely to see a specialist for

7 their mental health than their urban counterparts. [4] Stigma, lack of mental health care specialists,

8 and an overall insufficient healthcare workforce have been frequently cited as common barriers

9 to delivering mental health services to rural populations. [4-9]

10   In addition to disparities in mental health services, rural populations are also

11 disproportionately affected by chronic physical illnesses. Conditions such as cardiovascular

12 disease, stroke, and diabetes often have higher prevalence and have worse outcomes in the

13 presence of mental health disorders. [10-15] In fact, the greater the severity of mental illness, the

14 higher the incidence and excess mortality from many chronic physical illnesses, such as

15 cardiovascular and respiratory diseases. [16] Since comorbid mental illness has been demonstrated

16 to shorten lifespans in the presence of physical morbidities, [17] unmet mental health needs may be

17 an underlying factor contributing to this excess mortality in rural areas.

18   Given that rurality and chronic illness often share multiple and reciprocal pathways for

19 poor mental health, [15] [18-21] it is worth investigating rural chronically-ill patients' engagement with

20 mental health care. However, there is a paucity of research on the experiences of patients in rural

21 areas regarding their use of mental health care, and it is unknown if chronically-ill rural patients

22 have unique or excess barriers to mental health care than those without chronic illnesses.

1   In this paper we describe patient-reported barriers to seeking, receiving, and adhering to

2   mental health treatments in older rural patients with multiple physical comorbidities. We used a

3   modified version of Penchansky and Thomas's theory of access [22] to characterize barriers

4   reported by patients during semi-structured interviews across 6 dimensions of access for this

5   patient population. The information from this study was intended to identify areas for

6   intervention to expand access to mental health services in this high-risk, but underserved

7   population.

8   **Defining access**

9   Access to healthcare is a central problem to healthcare service provision and is one of the

10   most widely used concepts in discussions about healthcare policy. The concept of "access"

11   encompasses multiple dimensions and pathways that enable users to find, enter, and utilize

12   healthcare systems. Access is often defined in the literature as the degree to which characteristics

13   of the healthcare system fit the characteristics of the health system users, [22] although these

14   dimensions have been defined inconsistently and sometimes interchangeably by different

15   authors. [23] [24] For instance, Penchansky and Thomas uses the term "accommodation" to refer to

16   organizational factors that influence access, whereas Peters places organizational factors under

17   "availability".[25]

18   In 1981, Penchansky and Thomas developed a theory of access which is still widely used

19   to conceptualize problems of access in public health research.[23-28] The theory contained 5

20   dimensions: availability (supply and demand of services), accessibility (location of supply to

21   patients), accommodation (organization of system to accept patients), affordability (price of

22   services and patients' ability to pay for services), and acceptability (patient attitudes about the

23   immutability qualities about the service and service provider, and vice-versa). [22]

1   Noting that the original theory did not account for patient knowledge and understanding

2   of extant services, Levesque's split model of access, which describes parallel user and system

3   dimensions of access, posits that the "ability to perceive" a need for care is critical to healthcare

4   access. [24] Similarly, Saurman added a 6th dimension of access— awareness—to Penchansky and

5   Thomas's theory after an evaluation of a telepsychiatry program revealed that many users of

6   emergency mental health services were unaware of the existence of these services, what they

7   entailed, and who they were intended to serve. [23]

8   In the previous decade, there were calls for policy to increase intervention on select

9   dimensions of access from Penchansky and Thomas's model. For instance, the 2015 National

10   Rural Health Association (NRHA) released a policy brief calling for a "multi-pronged approach"

11   to mental health disparities through focusing on improving the availability, accessibility,

12   affordability, and acceptability of services. [29] Similarly, Smalley and colleagues identified three

13   key areas—accessibility, availability, and acceptability— to decrease rural mental health

14   disparities. [30] While these calls correctly identified a need to address multiple pathways

15   contributing to disparities in mental healthcare access, they disregard other important dimensions

16   of access. Further, while these provide helpful models for conceptualizing access, there is a

17   paucity of research grounding the utility of these theories in analyzing patients' lived

18   experiences. Rural patients with multiple comorbidities are particularly interesting to study, as

19   they paradoxically have relatively high contact with medical professionals, but still face

20   disparities in mental health care access.

21   **METHODS**

22   **Context and setting**

1   To fill this gap, we conducted a qualitative study of barriers and facilitators to rurally-

2   based mental health care. We conducted semi-structured interviews over the phone to allow the

3   researchers to easily interview ICARE patients from different locations across the state.

4   Interviews were analyzed by applying a modified Penchansky and Thomas's theory of access as

5   an analytical framework. This framework was chosen to guide our qualitative investigation

6   because 1) this framework is commonly used in public health discourse on problems of

7   healthcare access and 2) along with the dimension of awareness, it encompasses multiple broad

8   pathways by which access can be hindered. A sample of rurally-based patients with multiple

9   chronic physical comorbidities and anxiety and/or depression were enrolled from a previous

10   prospective, cluster-randomized, controlled clinical trial called Improved Cardiovascular Risk

11   Reduction to Enhance Rural Primary Care, or ICARE. [31 32] ICARE was conducted in 12 private

12   physician offices in Iowa. All the study procedures for both ICARE and this study were

13   approved by the university Institutional Review Board prior to beginning research activities.

14   **Overall study design:**

15   This is a qualitative study of semi-structured interviews. We used a prior study (ICARE)

16   as a convenience sample. Interviews were conducted over the phone and analyzed deductively in

17   NVIVO. [33]

18   **Eligibility**:

19   This study used patients from the original ICARE study as a convenience sample of

20   chronically-ill older patients receiving rurally-based mental health care. The original ICARE

21   study followed a two-step process for inclusion.[32] First, English-speaking males and females aged

22   50 or older who were seen at their primary care clinic within the previous 24 months with at least

23   one of the following conditions were identified: 1) diabetes 2) hypertension, or 3)

1 hypercholesterolemia with a history of peripheral artery disease, coronary artery disease, stroke,

2 transient ischemic attack, or diabetes. Second, patients had to have at least three chronic illnesses

3 or risk factors that could include the aforementioned diseases or any of the following: coronary

4 artery disease, myocardial infarction, stroke, transient ischemic attack, atrial fibrillation,

5 peripheral vascular disease, claudication, carotid artery disease, current smoking, or obesity.

6 Further, the 12 ICARE sites were selected because they provided care to predominately rural

7 patients.

8   ICARE patients were eligible to participate in the present study if they 1) self-reported

9 ever having a diagnosis of anxiety or depression or 2) had a diagnosis of anxiety or depression

10 reported in their electronic medical records, which was determined during the ICARE trial. The

11 justification for examining mental health in ICARE patients stemmed from a finding that anxiety

12 and depression were highly prevalent in this cohort, as 156 of the 302 patients enrolled in the

13 ICARE study had self-reported or diagnosed anxiety or depression during the trial, indicating the

14 potential for unmet care needs and elevated cardiovascular risk. [31]

15 **Recruitment**

16   We contacted 156 eligible patients through mailed letters containing the elements of

17 informed consent; our study obtained a waiver of written informed consent. Interested patients

18 then notified us of their willingness to participate by returning a postcard with their contact

19 information, contacting us via a dedicated study phone number, or the study email address.

20 Twelve ICARE patients could not be contacted due to changes in address made since the clinical

21 trial ended. The first author then contacted the patient to schedule a time for an interview over

22 the phone (online supplementary Appendix A). Patients could be contacted up to 3 times to

23 schedule an initial interview before being lost to follow-up. Patients could be interviewed up to 2

1 additional times to clarify questions that arose during the analysis process. Patients were offered

2 a $25 check voucher for every interview completed.

3 **Data collection**

4 Interviews were conducted from September 2017 – June 2018 by the first author. A semi-

5 structured interview guide (online supplementary Appendix B) was developed by the first and

6 second authors and contained questions about the patient's past and current experiences

7 obtaining mental healthcare and with different treatments, how they discussed their mental health

8 with providers, their knowledge of available resources, how they prioritized and balanced their

9 mental and physical healthcare needs, and what ideally their mental healthcare would include.

10 The interview guide underwent iterative revisions by the first and second authors by reviewing

11 interview audio and transcripts throughout the data collection process and adding or changing

12 questions to probe for additional or missing information. Interviews lasted between 20 minutes to

13 2 hours and were recorded. To protect patient privacy, identifying information was redacted from

14 audio files using Audacity. Audio files were transcribed using an online transcription service

15 (Rev.com).

16 **Data analysis**

17 Analysis of qualitative data was performed by deductive thematic analysis using a

18 modified theory of access described by Penchansky and Thomas and Saurman. The first and

19 second authors developed a codebook of descriptive codes that contained 6 broad dimensions of

20 access previously described in the literature as categories for analysis—accessibility, availability,

21 affordability, accommodation, acceptability, and awareness. Conflicts about coding were

22 resolved among the research team by discussing and revising the codebook. The final codebook

1   was developed by 2 researchers coding 2 (~10%) transcripts independently and comparing

2   results for agreement.

3   The analysis and reporting of the results were structured following the theoretical

4   concepts of Penchansky and Thomas[22] and the analytic methods of *Saurman et al.*[34] Following

5   the definitions in the codebook, transcripts were then coded line-by-line using NVIVO [33] for

6   barriers and facilitators to access to mental healthcare by the first author. The 6 dimensions of

7   access frame both the analysis and reporting of our data.

8   For the purposes of analysis, we used a broad definition of mental health services,

9   including specialized care, primary care, and more informal care settings, such as support

10   groups. Text was coded as a facilitator if it assisted the patient in receiving or adhering to mental

11   health treatment. Conversely, text was coded as a barrier if it prevented the patient from

12   receiving or sustaining mental healthcare. When all transcripts were coded, themes were defined

13   by comparing barriers and facilitators within each category for similarities and differences

14   endorsed by patients across interviews. Analysis stopped after data saturation was reached.

15   Themes with illustrative quotations are described in the results section.

16   **Patient and public involvement:**

17   Participants were not involved in any phase of the development, design, or writing of this

18   study.

19   **RESULTS**

20   19 prospective subjects contacted us with their interest in participating; 3 were lost to

21   follow-up and 1 decided not to be interviewed. We ultimately interviewed 15 patients. 4 patients

22   were re-interviewed for follow-up questions, resulting in a total of 19 interviews, at which data

1   saturation was reached. Data saturation was determined when no new or differing information

2   was gleaned from interviewing. We recruited a higher percentage of women than the original

3   ICARE study, and the majority of patients were female, white, and had an educational attainment

4   of 12 years or fewer (Table 1). Nearly three-quarters of patients had public insurance. We

5   recruited ICARE patients who, at the time of the original study, were either diagnosed with or

6   self-reported having histories of anxiety and/or depression; however, when asked during the

7   present study if they had ever received a mental health diagnosis, patients also reported: post-

8   traumatic stress disorder (PTSD), panic disorder, bipolar-II, substance abuse, "anger issues," and

9   prior suicidality. At the time of the interview, most (73%), but not all, patients self-identified as

10   ever having a mental health diagnosis, despite meeting at least one of the ICARE criteria.

11   Patients rated both their physical and mental health as important health priorities.

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1   **Table 1: Patient characteristics (n= 15)**

Variable	Mean (SD)	N (%)
Age (range 53-71 years)	61.7 (5.1)	
Gender		
Female		12 (80)
Male		3 (20)
Race & ethnicity		
White, non-Hispanic		14 (93.33)
Black		1 (6.67)
Educational attainment		
≤ 12 years		9 (60)
Associates or technical degree		4 (26.67)
College or higher		2 (13.33)
Insurance type		
Medicare		7 (46.67)
Medicaid		4 (26.67)
Private		3 (20)
None/self-pay		1 (6.67)
ICARE recruitment criteria		
Diagnosis of depression		9 (60)
Diagnosis of anxiety		9 (60)
Self-reported depression		10 (66.67)
Self-reported anxiety		12 (80)
Ever had a mental health diagnosis		11 (73.3)
Ever took psychiatric medication		13 (86.67)
Currently taking psychiatric medication		12 (80)
Ever saw a mental health specialist		13 (86.67)
Psychiatrist		6 (46.15)
Psychiatric nurse		1 (7.69)
Therapist or counselor		10 (76.92)
Currently seeing a mental health specialist		4 (26.67)
Psychiatrist		2 (13.33)
Therapist or counselor		2 (13.33)
Self-rated importance of addressing mental health (1= least important, 10= most important)	8.93 (1.73)	
Self-rated importance of addressing physical health (1= least important, 10=most important)	9.46 (.88)	

2

1   A requirement of enrolling in the ICARE study was that all patients had a primary care

2   provider, thus, in this sub-study all patients had some level of access to medical care. Most

3   patients were receiving mental health services through their primary care providers. A majority

4   of patients had seen mental health specialists (either a psychiatrist, psychiatric nurse, or a

5   therapist) at some point in their lifetime. However, only slightly more than a quarter were

6   currently seeing a provider other than their PCP for their mental health. Despite this current level

7   of access, patients reported a myriad of barriers to mental health care in rural settings, which are

8   summarized in Table 2 and described below.

1 **Table 2: Dimensions of access and patient-reported barriers to mental health care**

Dimensions	Definition	Sub-themes	Patient-reported Barriers	Patient-reported Facilitators
Accessibility	Services are offered within a reasonable proximity to patient in terms of time and distance.	• Differences in distance to providers • Transportation	• Distance to mental health specialists/resources • Lack of motility • Severe chronic illness	• Local mental health services • Social support
Availability	Services physically exist, are in adequate supply, and can meet the volume and needs of the patients served.	• Identifying brick-and-mortar facilities and workforce	• Difficulty establishing long-term relationships with providers • Lack of facilities offering mental health services	• Dedicated mental health facilities • PCP manages mental health care
Affordability	Cost to consumer and the financial viability of service provider. Includes payment from multiple funding streams.	• Insurance policy for mental health services and treatments • Out-of-pocket cost	• Lack of mental health parity • Pharmaceuticals not covered • High co-pays	• Complete and on-going coverage for services
Accommodation	Clinic operations are organized such that patients can utilize services easily; services are easy and convenient to	• Communication with the patient • Processes for initiating and changing treatment	• Communication channel incompatible with patient • Waiting lists/waiting times • Crisis care unavailable	• Routine screening and monitoring procedures • PCP makes referral to a specific mental health provider

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15

	obtain and use.		• Difficulty receiving referrals	
Acceptability	Patient attitudes about the personal and practice characteristics of a provider or qualities of a healthcare service.	• Quality of the patient-provider relationship • Quality of the healthcare service	• Provider "doesn't listen" • Disrupting long-term clinical relationships • Unpleasant medication side-effects	• Non-judgmental listening • Joint decision-making • Minimal medication side-effects
Awareness	Patients can identify that some form of services exist, can be reached, and have an impact on the health of the individual.	• Mental health literacy • Understanding of the mental health system	• Inability to locate resources • Poor health literacy • Poor knowledge of mental health system	• PCP educates patient on diagnoses, treatments, and options

1

Accessibility

Accessibility refers to the relationship between patients, the location of services, and the time spent traveling to obtain them.

Differences in distance to providers

Patients indicated differences in accessibility for PCPs and mental health professionals, such as therapists and psychiatrists. Most patients reported that their PCP practiced locally and was easier to access in terms of time and distance; thus, for many, their PCP was the most accessible provider for obtaining mental health services. Patients faced more difficulty traveling to psychiatrists, therapists, and support groups due to distance and time spent traveling. Patients frequently estimated traveling times of a minimum of 45 minutes to the next largest town that would offer specialist resources. Some patients noted that while some form of specialist resources might be available locally, they felt that other places had better resources than what was immediately available. One respondent stated:

> The bottom line is if you need help, you can get it, but the degree
> of expertise that lies in these people is not like a big city. This is a
> different caliber of doctor. (Patient 3, M, aged 62)

Transportation

Further, transportation was also a barrier for rural and chronically ill patients. Some patients reported a lack of mobility or independence for traveling, such as not having a driver's license, broken vehicles, or being mostly house-bound from severe chronic illness, such as cancers and chronic pain; these patients relied on friends and family to help them get to medical appointments.

1   In contrast, facilitators that enabled patients to obtain mental health services were having

2   providers and mental health workforce practicing locally, having a PCP with expertise in treating

3   mental health concerns, and having friends or family to take them to their appointments.

4   **Availability**

5   Availability refers to the relationship between quantity and quality of services and patient

6   demand for services. Patients reported many factors that impacted the availability of mental

7   health services.

8   *Identifying brick-and-mortar facilities and workforce*

9   During the course of the ICARE study, and prior to these interviews, the governor

10   privatized Medicaid and also closed several mental health facilities in Iowa. Notably, several

11   patients discussed the closure of state-run mental health facilities and psychiatric units as an

12   indication of dwindling resources or opportunities for receiving mental healthcare, even though

13   none had disclosed having been patients at those facilities. These closures gave some patients the

14   perception that mental health services were overall in short supply. As one patient stated:

15   In our town it seems like people can't get help. They'll end up

16   going to jail and the jail tries pushing them off onto mental health

17   or vice versa. There should be a place that they can go, but every

18   time you turn around they're wanting to close them. … Doctors are

19   doing okay as far as I'm concerned in this town, but it's their

20   limited resources. (Patient 13, F, aged 60)

21   In addition to a shortage of physical facilities, patients often noted a lack of providers,

22   particularly those with specialist expertise. Patients who were currently receiving specialized

1 mental health care noted that their providers had high patient loads and it was difficult to get an

2 appointment with a specialist provider, particularly psychiatrists. Again, PCPs were often easier

3 to see when problems arose:

4   My psychiatrist is a little difficult because there are so many

5   people at [clinic], mental health runs rampant over there. My

6   doctor's appointments are easier. I called on Friday, had an

7   appointment Monday. (Patient 10, F, aged 67)

8   In contrast to the aforementioned barriers, facilitators to availability included the PCP

9 having special training or expertise in psychiatry, and the clinic having in-house mental health

10 specialists.

11 **Affordability**

12   Affordability refers to the ability for healthcare services to be reimbursed through

13 different funding streams.

14 *Out-of-pocket cost*

15   While all patients in this study had some access to physical and mental healthcare in

16 terms of paying for services, the ability to pay for services was dependent on the type of provider

17 and degree of insurance coverage. Although receiving some types of mental health care from

18 PCPs was often a more affordable option, receiving specialist services was less frequently

19 affordable, with patients reporting paying high copays for clinic visits and medications. Some

20 patients were retired or did not earn enough to cover copays. Insurance coverage was particularly

21 problematic for patients seeking therapists:

1   I could always go to a psychologist, but it costs money. I live on a

2   fixed income with Social Security. I don't have extra money that I

3   could just say, "Gee, I think I'll make an appointment with a

4   therapist." (Patient 10, F, aged 67)

5   *Insurance policy for mental health services and treatments*

6   Patients in this sample were largely insured through Medicare and Medicaid (~73%),

7 which had limitations due to the low number of mental health professionals accepting subsidized

8 insurance. The recent changes in Iowa's privatized Medicaid system left some patients with gaps

9 in their mental healthcare coverage after one managed care organization dropped out of the

10 program, which in turn impacted the availability of treatment options. For instance, one patient

11 recalled recently being forced to cancel appointments with his therapist after the change. Another

12 patient recalled that insurance companies were not willing to cover more expensive depression

13 medications prescribed by her physician:

14   Now we are living by what the insurance companies tell us. And I

15   suppose that even includes the depression type drugs… They

16   won't pay for it. 90% of the time it seems that insurance

17   companies are rejecting what the doctor says. Get to the pharmacy

18   and you have to play "find out what we can do for you." (Patient 1,

19   F, aged 63)

20   Factors that made receiving mental healthcare more affordable was having insurance

21 policies that enabled mental health parity for services. While not personally experienced by

22 patients, some expressed a desire for more low-cost and community-based mental health

23 programs for individuals facing financial barriers.

Accommodation

Accommodation refers to the ease and convenience of using services. Patients described

several ways that extant services were made less accessible due to organizational and policy

factors within primary care and mental health clinics.

Communication with the patient

First, communication with the patient influenced adherence and appointment attendance.

Clinics did not always communicate to the patient through their preferred channels, meaning that

reminders about upcoming appointments and important updates about the patients' care were

sometimes missed. In the context of mental health services, the lack of communication between

patients and providers could be disruptive to their care. This is exemplified by one patient's

account how her clinic did not notified her about her mental health provider leaving:

> I was devastated because my lady that I go see just up and left.
>
> And I'd been seeing her for 10 or 15 years. She went to a different
>
> job down 30 miles from here. I started crying right there. She let
>
> people know a month in advance, but I was seeing her every 6
>
> weeks. So needless to say I did not see anybody. (Patient 13, F,
>
> aged 60)

Processes for initiating and changing treatment

Further, clinical protocols such as depression or anxiety screening may influence how

readily patients initiate or alter aspects of their mental healthcare. For instance, some patients

receiving mental health services through their PCP said their physician never asked them about

their emotional well-being and had only begun treatment after telling their physicians that they

1 suspected they had depression; these patients felt responsible for initiating discussions about

2 their mood and treatment outcomes. However, not all patients were willing to initiate these

3 conversations unprompted. As one patient suggested:

4   Every time I go to see [my doctor], he asks me if I'm depressed.

5   But I don't know that every doctor does that. I think that mental

6   health sometimes is overlooked, but sometimes it's the root of

7   some of your physical problems. So I think the doctors need to

8   approach it as my doctor does and ask me how I'm doing mentally.

9   (Patient 9, F, aged 72)

10   Referral policies and procedures also impacted the ability of patients to receive

11 specialized mental healthcare. Many patients were uncertain about where to receive additional or

12 specialized services and relied on their PCPs for referrals. However, some patients had trouble

13 requesting and receiving referrals to other providers or resources. This became a significant

14 barrier when patients needed services beyond what their PCP could provide:

15   I know my doctor never suggested talking to anybody or doing

16   anything more, and you can't hardly get referrals to go see other

17   people without the doctors. … You almost always have to have

18   that referral. And then its question is who's good and who's not

19   good, and I don't know how to figure that part out. (Patient 1, F,

20   aged 63)

21   Patient 1 ultimately never received a referral but decided to stay with her PCP due to her

22 proximity to the clinic. Even after finding specialized care, other patients found that it was

difficult to initiate services with new providers for different reasons. Some facilities were not

accepting new patients or were not willing to allow clients to see other therapists within their

facility when patients requested a change. These problems then prompted patients to cease care

with that provider in favor of seeking a more accommodating one, as exemplified by this patient

who had requested to see a different therapist:

> By the end of 5 months, I asked to see someone else. They told me
>
> that they don't do that. So I never went back. (Patient 10, F, aged
>
> 67)

Facilitators mentioned by patients were described as procedures that made receiving and

adhering to clinical care easier. For instance, patients appreciated receiving reminders of up-

coming appointments through phone calls. Further, screening and routine monitoring of patients'

symptoms were important facilitators to patients. Finally, some patients in this sample described

how their PCP made it easier to receive additional care by making referrals to a mental health

provider; sometimes more than one referral was needed in order for patients to find a provider

they felt could help them.

Acceptability

Acceptability refers to patient attitudes about the characteristics of a provider or a

healthcare service and vise-versa. In other words, acceptability describes the degree to which

patients and providers tolerate the immutable qualities of one another or the service being

offered. In this sample, the most significant patient-reported barriers impacting acceptability

were poor relationships with the provider and dissatisfaction with aspects of the treatment.

Quality of the patient-provider relationship

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1   Patients described the relationship they had with any mental healthcare provider as one of

2   the most significant determinants of whether they would continue seeking mental healthcare

3   care. A negative experience with a mental health provider could prevent the patient from

4   returning for subsequent visits. Sometimes this resulted in a further delay for seeking treatment

5   with other providers for long periods of time ranging from months to years:

6   I saw that therapist I think in 2010. Didn't work for me. I just didn't

7   feel like I was talking to somebody who understood what I was

8   going through. That's really difficult for me. Most of the time I

9   never finished the sessions. (Patient 10, F, aged 67)

10   At the time of the interview in 2018, this patient had experienced a recent increase in her

11   anxiety. Only when a provider she trusted, her long-term psychiatrist, suggested that she talk to a

12   therapist did she reluctantly consider going again, stating, "I'm going to try it again. I'm very

13   hesitant about doing it."

14   Notably, patients overall did not feel that providers' professional backgrounds (such as

15   psychiatry or family medicine) were as important as their interpersonal skills. When asked about

16   what they were looking for in a mental health provider, patients described the ideal provider as

17   someone who was trustworthy; regardless of their professional background, providers should be

18   comfortable discussing mental health concerns and patient histories, understanding of their

19   feelings and preferences, and be an active, empathetic listener. Patients valued being able to

20   communicate openly about their experiences without fear of judgement. Patients felt that being

21   truly heard and understood was paramount to their own recoveries:

22   I've noticed that some doctors are kind of like "Oh, I don't wanna

23   talk about that."... If you're gonna shy away from this, what else

1 are you gonna shy away from? So I didn't feel comfortable with

2 them, and I was like "Forget it". … You've gotta be able to talk to

3 them about mental health, your physical health. (Patient 11, F,

4 aged 54)

5 Several patients reported having prior negative experiences with a provider that they saw

6 for their mental health. Thus, patients were eager to retain providers they liked for as long as

7 needed. Patients felt that having a positive long-term relationship with a provider enabled them

8 to receive better mental healthcare, as it enabled their provider to interpret their affect accurately:

9 I think from all the times that I've went and seen her that she knew

10 that something's wrong even if I didn't want to tell her about it.

11 And I think that, to me that showed me that she really cared. That

12 she knew my thoughts and feelings. (Patient 13, F, aged 60)

13 Patients also discussed disruption of valued clinical relationships as significant barriers to

14 receiving mental health care; the impact of providers leaving their clinics often meant that the

15 patient would have to start looking for trusted providers again. Sometimes this left a gap in the

16 management or provision of their mental health care for several months. Since patients in this

17 sample preferred to stay with the same trusted provider, disruptions in clinical relationships were

18 often emotional experiences, as it was for one patient whose long-term PCP, who also managed

19 her depression and anxiety treatment at the time, retired:

20 I was so upset. I told him, "I'm not happy about this," when he let

21 us know. We got a letter and I just felt like crying because I did not

22 want that to ever happen. I always thought "I'll have him forever."

23 (Patient 8, F, aged 70)

1   Additionally, patients valued being able to collaborate with their providers on treatment

2   decisions. Some patients felt that their previous providers didn't respect their desire to alter

3   aspects about their treatment or therapy, which lead to them ceasing care with that provider. This

4   seemed especially true for patients who wished to discontinue medications with deleterious side-

5   effects:

6   Well, I had told [psychiatrist] my prior experience with certain

7   drugs. … And he was coming up with these diagnoses that really

8   were not pertinent to me. He knew it all, you know. … I already

9   told him that I don't take those drugs and that I've tried them in the

10   past and they just haven't worked for me. We didn't have a very

11   good connection. (Patient 3, M, aged 62)

12   While patients said they were generally open-minded about their providers'

13   recommendations, they framed providers' willingness to negotiate treatment options to find the

14   best fit as an indication that their providers truly understood their needs. As the previous patient

15   stated:

16   If they're willing to meet me halfway, we get along just fine. But

17   just don't talk. You also have to listen. A lot of doctors don't

18   wanna listen. You throw up a couple of symptoms, this and that,

19   they've already got a diagnosis. But they really don't know your

20   history. … That's why I wouldn't want to lose the doctor I have

21   right now. (Patient 3, M, aged 62)

22   *Quality of the healthcare service*

1   Finally, patients described different ways that their treatment options were not compatible

2   with patients in terms with their clinical or personal goals. Many patients recounted at least one

3   time they had been dissatisfied with their psychiatric medication. However, sometimes patients

4   felt that medication was not right for them, and sought other services, such as counseling or

5   therapy, but also encountered difficulties finding or asking for alternatives:

6   There was a point when I got so depressed, and all the doctor

7   wanted to do was give me pills. Beyond that, they weren't too

8   interested. So you take the pills, you sleep a lot…you really don't

9   get any better. … They may help, but it won't get to the problems,

10   of how to really deal with the way you're feeling and things. … I

11   just felt kind of let down…you know, when I did get to the point

12   where I asked for [help], it wasn't like it was a high on her list. She

13   gave a prescription but that's not it. (Patient 1, F, aged 63)

14   **Awareness**

15   Awareness refers to patients' ability to perceive and locate extant services, as well as

16   their health literacy. In other words, patients can identify that some form of services exist, can be

17   reached, and have an impact on the health of the individual. Overall, patients said they were

18   largely uncertain about where to go for mental health concerns and were less familiar with extant

19   options for receiving mental health services than their physical health care.

20   *Understanding of the mental health system*

21   Patients had varying knowledge of Iowa's mental health system and mental healthcare

22   options. For instance, most patients who had received some form of services from a mental

23   health specialist, such as a psychiatrist or therapist, could not describe how different treatment

1   options worked. Further, some patients could not readily distinguish between different provider

2   types, including their own service providers, and were unsure of how to access services offered

3   by different provider types. While PCPs were more accessible and available than other provider

4   types, not all patients were aware that they could or should discuss mental health concerns with

5   their PCP, as one patient put it:

6   Usually if you're going to the doctor you may quiz them about

7   some other things. But it's not like I make an appointment just to

8   go and discuss mental. I go in to do my *medical* stuff and discuss

9   it. (Patient 1, F, aged 63, emphasis in original)

10   Patients differed in their abilities and preferred channels for finding out information about

11   their conditions, local resources, and treatment options. While patients primarily could only

12   name the places that they had previously received services, over the course of the interviews they

13   mentioned several preferred channels for researching other options, including the local

14   phonebook or service directory, magazines, and local churches. While one patient said they

15   would research their options on the internet, two others said they were unable to use internet

16   searches to find more information (one didn't have a computer, the other didn't know how to

17   search). Many patients felt that extant mental health services were not apparent to those in need.

18   As one patient stated:

19   Some [mental health services] don't advertise, so a lot of people

20   don't know … what's available. You see all these other

21   advertisements, but you never see where to go for mental health

22   help. Not once have I seen help for that. So I don't think people

23   know where to turn. (Patient 11, F, aged 54)

1 *Mental health literacy*

2 Another reported barrier that resulted in delaying seeking treatment was an initial lack of

3 knowledge about common mental health disorders. Patients in the sample usually described

4 learning about mental health conditions and services only after experiencing them first-hand. For

5 instance, many patients reported that they first learned about anxiety or depression after they had

6 been diagnosed with the condition. In some cases, patients learned about these conditions from

7 family and friends with similar experiences, who then told them how to seek care.

8 Facilitating awareness, PCPs emerged as one of the most important sources for education

9 and information for patients, as patients reported relying heavily or even solely on their PCPs for

10 information about mental health conditions. When asked where they would go if they had

11 questions or developed new problems with their mental health, most patients said they would

12 return to their PCP. As one patient stated in her advice to patients going through similar struggles

13 with their mental health, one patient responded:

14 Go to their family doctor and tell them exactly what they're

15 feeling. It's the only way that they can get any guidance. (Patient 8,

16 F, aged 70)

17 **DISCUSSION**

18 This study examined barriers experienced by a sample of 15 rural adults managing

19 multiple physical conditions as well as depression and/or anxiety. We found that while patients

20 in the study generally believed that treating both their physical and mental health were important

21 priorities, long-term mental healthcare with any one provider was often hindered by multiple,

22 sometimes over-lapping barriers. Except for the dimension of accessibility, we did not observe

1 chronic illness contributing to excess barriers to receiving mental health services among our

2 sample. Despite this, most patients experienced at least one barrier to receiving mental healthcare

3 in their lifetimes. This study is the first qualitative investigation, to our knowledge, of barriers

4 experienced by rural Iowans after the privatization of Medicaid and the state-wide shift towards

5 community-based mental health services, which changed the distribution and delivery of services

6 compared to previous years. This study contributes to our understanding of the impact of this

7 changing context for delivering rural mental health services.

8 While studies about rural US adults with comorbid physical and mental comorbidities are

9 particularly limited, findings from this study both confirm and augment those of extant research

10 on rural health disparities. For example, the importance of a good patient-doctor relationship has

11 been found in previous studies [35] and may be more important than other factors, such as distance

12 to services, for rural patients. [36] The present study suggests that shared decision-making between

13 the patient and provider, as well as clinical organization, may facilitate positive patient-physician

14 relationships and greater adherence to treatment. Further, similar to *Saurman et al*, we found that

15 patients' awareness of extant mental health services was indeed a critical dimension of access in

16 rural populations; [23 37] our findings indicate rural social networks and public advertisement of

17 mental health services in clinics or in the community may be viable avenues for promoting

18 service utilization by facilitating awareness. While strengthening the role of the PCP in

19 managing common psychiatric concerns, such as anxiety and depression, has been proposed as

20 an intervention to improving access in rural areas, [38] our results complicate that strategy, as

21 patients in our study felt that PCPs, while the most accessible, were not always the most

22 acceptable option for addressing their mental health concerns. Finally, while other studies of

23 mental health service utilization by rural individuals demonstrate how stigma affects the

1 acceptability of services, [39] our study finds that other issues, such as feeling understood by the

2 provider, impact the acceptability of services, even among patients who actively want help.

3   Our study has important implications for intervention planning. As reported by the

4 study's patients, barriers to access were often related to one another. For instance, under

5 accessibility, patients reported unreliable transportation arrangements or mobility issues that

6 made traveling more difficult than other rural individuals. Similarly, under the dimension of

7 availability, patients felt they had few local options and would have to travel to find care. Thus,

8 utilizing multiple pathways to deliver mental health services either locally or remotely may be

9 especially important for rural individuals with limited mobility. Likewise, the patient-provider

10 relationship was a significant finding in both the dimensions of availability (difficulty

11 establishing clinical relationships) and acceptability (relationship and communication with

12 provider), and strongly influenced patients' desire to return for appointments. Finally, awareness

13 was pertinent to both the dimensions of availability and acceptability, as it influenced patients'

14 knowledge of how to seek mental healthcare, as well as shaped patients' expectations of clinical

15 outcomes. It should be noted that as our study was restricted to patients over the age of 50, the

16 barrier of awareness (such as the ability to use internet searches) could be contributed to

17 participants' age rather than chronic illness or rural status. Nevertheless the relative invisibility

18 of mental health services reported by this sample may be an important finding for providers and

19 public health practitioners who wish to promote local services. Overall, these results indicate that

20 interventions aimed at this population should account for multiple barriers to access.

21   This study had several limitations. First, patients in this study were largely female and

22 nearly exclusively white. This may reflect the gender and race differences in help-seeking

23 patterns[40 41], healthcare utilization[41 42], and diagnosis rates[43 44], which has been well-documented

1   in other studies. Further, the barriers to access experienced by Iowans of other racial and ethnic

2   backgrounds may not be represented in these findings, indicating a need to research the

3   experiences of racial and ethnic minorities obtaining rural mental healthcare, specifically.

4   Second, while small sample sizes are often used in qualitative work due to the volume of data

5   generated in qualitative analysis, we only recruited ~12% and ultimately interviewed ~9% of

6   eligible ICARE patients. This low-response rate may be a product of stigma against mental

7   health disorders. Further, given the low response rate, it is possible that our findings contain

8   selection bias, and as such the experiences represented here differ considerably from the general

9   population. Further, we note that while all patients met ICARE criteria for inclusion, not all

10   endorsed having a history of mental health diagnosis; this may reflect different levels of mental

11   health literacy or understandings of mental health topics and concepts in this rural older

12   population.

13   This study also had a number of strengths. We believe that our recruitment strategy using

14   a convenience sample of rural patients from the ICARE study allowed us to interview in-depth

15   patients from a number of towns across rural Iowa, thus allowing us to have a wide geographic

16   sampling within the state and within multiple hospital and clinic systems. Further, our semi-

17   structured and iterative approach to writing an interview guide allowed us flexibility to probe for

18   issues that were important to participants. Finally, our analytic framework of a modified theory

19   of access from Penchansky and Thomas allowed us to account for and characterize multiple

20   interrelated barriers at once.

21   **CONCLUSION**:

22   This study offers important insight into the real-life experiences of rural individuals with

23   multiple comorbidities with seeking mental healthcare, such as the importance of the patient-

1 provider relationship in care-seeking behaviors, understanding of the diversity of healthcare

2 settings and provider types, and critical organizational and policy-level barriers. It is important

3 that interventions are grounded in the needs of intended service users; in this case, interventions

4 targeting rural individuals with multiple comorbidities may need to account for multiple and

5 overlapping barriers.

6

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FOOTNOTES:

Author contributions: LP and KAK conceived and designed the study. BLC was the principal investigator who designed and conducted the original ICARE study from which this sample was obtained. LP and KAK participated in the recruitment of the subjects for this sub-study. LP and KAK participated in the collection, analysis, and interpretation of data. LP drafted the manuscript. KAK and BLC critically reviewed and approved this manuscript for publication.

Patient consent: obtained

IRB approval: Ethical approval for study activities was obtained from the University of Iowa IRB (08/28/2017).

Data availability statement: No additional data are available.

APPENDIX A: Phone script

Hello, my name is [NAME], and I am a Co-Investigator for the ICARE study you and your clinic participated in. As part of the study, a clinical pharmacist from the University of Iowa collaborated with clinic physicians in order to improve health outcomes for patients. We now hope to conduct an interview over the phone with 3-4 patients from that clinic so we can identify ways to improve mental health services in rural care settings. I received [an email or a postcard] indicating that you may be interested in participating in this interview over the telephone. The interview will take about 30-60 minutes. You also may be asked to participate in a follow-up 30-minute interview for clarification of questions that arise during the analysis of interview data. If you are interested in participating in a follow-up phone interview, you will be asked to leave a phone number and best time of day for phone contact.

Participation in this interview is completely voluntary. Is this interview something you may be interested participating in?

> *{If YES}* Do you have some time to do the interview now? Or we could set up a later time to do the interview if you don't have time now or wanted more time to think about participating.

> *{If NO}* I thank you for your time. Have a good day.

Let me go over some things before we begin.

If you have any questions, please feel free to ask me. Also, if you don't want to answer any questions just let me know.

With your permission, we will be recording this interview to ensure we accurately record what you say and so we can review your responses.

All information will be kept strictly confidential. I will use a random study ID number to identify you once we start recording.

Do you have any questions for me before we begin?

OK, I will begin recording now.

Hi, this is *[NAME]*. I am speaking with participant #_____.

Today's date is _____.

Thinking back on your interactions in health care clinics, please answer the following questions.

[interview questions]

APPENDIX B: Example interview questions

Interview guides were developed iteratively to probe for missing information.

Questions about patient's mental health service utilization

1. Have you ever been diagnosed with anxiety or depression?
2. Do you recall a provider ever asking you about your [anxiety/depression/mental health]? What about your mood?
   a. *{IF YES}*
      i. How did he or she ask?
      ii. When go to visit your healthcare provider, how often does he/she ask you about it? Every visit? Every few visits?
3. How is easy for you to talk about [anxiety/depression/mental health] with your provider?
4. Think about how your provider addresses your healthcare needs. Do you feel your provider thinks [anxiety/depression] is important to address?
   a. {IF PATIENT HAS DX}
      i. Do you think they spend enough time addressing your [anxiety/depression]?
5. Are you currently receiving any kind of treatment or therapy for [anxiety/depression] or any other mental health or mood issue?
   a. *{IF YES}*
      i. How satisfied are you with your current treatment?
      ii. Are there things you wish your provider would do differently regarding your mental health care?
         1. *{IF NO}*
            a. What do you like about their approach?
   b. *{IF NO}*
      i. Have you in the past?
6. Was there a time you needed care for [anxiety/depression] symptoms but could not or did not receive any?
   a. *{IF YES}*
      i. What would have helped you during that time?
7. Overall, what do you think would improve treatment of anxiety/depression for people experiencing it?

Healthcare priorities

8. Think about your healthcare needs and priorities. On a scale of 1-10, how important or urgent is treating your [anxiety/depression]?
      i. Why did you pick that numbers verses a [higher/lower] number?

   ii. On a scale of 1-10, how important or urgent is treating your physical healthcare?

9. Do you have other health issues that trouble you a lot?

  b. {If YES}

   i. How do you balance those with addressing your mental health?

Patient preferences/conclusion:

10. In an ideal world, what would you look for in a mental health provider?
11. What would help you manage your [anxiety/depression] the most?
12. If you needed help with your mental health, who would you like to call?
13. Where would someone in your area go if they wanted help for their mental health?
14. Do you have any advice for patients struggling with a mood disorder?
15. Finally, do you have any recommendations for providers treating patients for [anxiety/depression/mood disorders]?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.