

# 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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## 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 older adults' 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 and facilitators to mental healthcare access. 19 interviews were analysed deductively for barriers using a modified version of Pechansky and Thomas's theory of access as an analytical framework.

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

**Participants** 15 rural Iowan older adults 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 indicate that 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.

## INTRODUCTION

Mental illness is one of the largest contributors to disease and disability in the USA.<sup>1 2</sup> 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.<sup>3</sup> Further, rural individuals being treated for their mental health

## Strengths and limitations of this 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.
- Participants were asked about their lived experiences and barriers encountered in seeking mental healthcare in rural settings.
- This study is the first qualitative investigation, to our knowledge, of barriers experienced by older rural Iowans after the privatisation of Medicaid and the state-wide shift towards community-based mental health services, which changed the distribution and delivery of services compared with previous years.
- The main limitations of this study was that it used a small, largely homogeneous population which may have limited generalisability and possible selection bias; experiences of rural patients of other racial and ethnic backgrounds may not be represented in the study findings.

have fewer mental health visits and are less likely to see a specialist for their mental health than their urban counterparts.<sup>4</sup> Stigma, lack of mental healthcare specialists and an overall insufficient healthcare workforce have been frequently cited as common barriers to delivering mental health services to rural populations.<sup>4-9</sup>

In addition to disparities in mental health services, rural populations are also disproportionately affected by chronic physical illnesses. Conditions such as cardiovascular disease, stroke and diabetes often have higher prevalence and have worse outcomes in the presence of mental health disorders.<sup>10-15</sup> In fact, the greater the severity of mental illness, the higher the incidence and excess mortality from many chronic physical illnesses, such as cardiovascular and respiratory diseases.<sup>16</sup> Since comorbid mental illness has been demonstrated to shorten lifespans in the presence of physical morbidities,<sup>17</sup> 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,<sup>15 18–21</sup> it is worth investigating rural chronically-ill patients' engagement with mental healthcare. However, there is a paucity of research on the experiences of patients in rural areas regarding their use of mental healthcare, and it is unknown if chronically-ill rural patients have unique or excess barriers to mental healthcare than those without chronic illnesses.

In this paper we describe patient-reported barriers to seeking, receiving and adhering to mental health treatments in older rural patients with multiple physical comorbidities. We used a modified version of Pechansky and Thomas's theory of access<sup>22</sup> to characterise barriers reported by patients during semi-structured interviews 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 utilise 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,<sup>22</sup> although these dimensions have been defined inconsistently and sometimes interchangeably by different authors.<sup>23 24</sup> For instance, Pechansky and Thomas uses the term 'accommodation' to refer to organisational factors that influence access, whereas Peters places organisational factors under 'availability'.<sup>25</sup>

In 1981, Pechansky and Thomas developed a theory of access which is still widely used to conceptualise problems of access in public health research.<sup>23–28</sup> The theory contained five dimensions: availability (supply and demand of services), accessibility (location of supply to patients), accommodation (organisation 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 vice versa).<sup>22</sup>

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.<sup>24</sup> Similarly, Saurman added a sixth dimension of access — awareness — to Pechansky and Thomas's theory after an evaluation of a telepsychiatry programme 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.<sup>23</sup>

In the previous decade, there were calls for policy to increase intervention on select dimensions of access from Pechansky and Thomas's model. For instance, the 2015 National Rural Health Association released a policy brief calling for a 'multi-pronged approach' to mental health disparities through focusing on improving the availability, accessibility, affordability and acceptability of services.<sup>29</sup> Similarly, Smalley and colleagues identified three key areas — accessibility, availability and acceptability — to decrease rural mental health disparities.<sup>30</sup> 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 conceptualising access, there is a paucity of research grounding the utility of these theories in analysing patients' lived 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 healthcare access.

## METHODS

### Context and setting

To fill this gap, we conducted a qualitative study of barriers and facilitators to rurally-based mental healthcare. We conducted semi-structured interviews over the phone to allow the researchers to easily interview ICARE patients from different locations across the state. Interviews were analysed by applying a modified Pechansky and Thomas's theory of access as an analytical framework. This framework was chosen to guide our qualitative investigation because (1) this framework is commonly used in public health discourse on problems of healthcare access and (2) along with the dimension of awareness, it encompasses multiple broad pathways by which access can be hindered. A sample of rurally-based patients with multiple chronic physical comorbidities and anxiety and/or depression were enrolled from a previous prospective, cluster-randomised, controlled clinical trial called Improved Cardiovascular Risk Reduction to Enhance Rural Primary Care, or ICARE.<sup>31 32</sup> 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 analysed deductively in NVivo.<sup>33</sup>

### Eligibility

This study used patients from the original ICARE study as a convenience sample of chronically-ill older patients receiving rurally-based mental healthcare. The original

ICARE study followed a two-step process for inclusion.<sup>32</sup> 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) hypercholesterolaemia with a history of peripheral artery disease, coronary artery disease, stroke, transient ischaemic attack or diabetes. Second, patients 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 ischaemic attack, atrial fibrillation, peripheral vascular disease, claudication, carotid artery disease, current smoking or obesity. Further, the 12 ICARE sites were selected because they provided care to predominately rural patients.

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.<sup>31</sup>

### Recruitment

We contacted 156 eligible patients through mailed letters containing the elements of informed consent; our study obtained a waiver of written 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 (online supplementary appendix A). 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 US\$25 cheque voucher for every interview completed.

### Data collection

Interviews were conducted from September 2017 to June 2018 by the first author. A semi-structured interview guide (online supplementary appendix B) 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 prioritised 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 min 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 Pechansky and Thomas and Saurman. The first and second authors developed a codebook of descriptive codes 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.

The analysis and reporting of the results were structured following the theoretical concepts of Pechansky and Thomas<sup>22</sup> and the analytical methods of Saurman *et al.*<sup>34</sup> Following the definitions in the codebook, transcripts were then coded line-by-line using NVivo<sup>33</sup> for barriers and facilitators to access to mental healthcare by the first author. The six dimensions of access frame both the analysis and reporting of our data.

For the purposes of analysis, we used a broad definition of mental health services, including specialised 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, themes were defined by comparing barriers and facilitators within each category for similarities and differences endorsed by patients across interviews. Analysis stopped after data saturation was reached. 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; three were lost to follow-up and one decided not to be interviewed. We ultimately interviewed 15 patients. Four patients were reinterviewed for follow-up questions, resulting in a total of 19 interviews,

at which data saturation was reached. Data saturation was determined when no new or differing information was gleaned from interviewing. We recruited a higher percentage of women than the original ICARE study, and 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 who, at the time of the original study, were either diagnosed with or self-reported having histories of anxiety and/or depression; however, when asked during the present study if they had ever received a mental health diagnosis, patients also reported: post-traumatic stress disorder, panic disorder, bipolar II, substance abuse, 'anger issues' and prior suicidality. At the time of the interview, most (73%), but not all, patients self-identified as ever having a mental health diagnosis, despite meeting at least one of the ICARE criteria. Patients rated both their physical and mental health as important health priorities.

A requirement of enrolling in the ICARE study was that all patients had a primary care provider, thus, in this substudy 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 primary care physician (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 summarised in table 2 and described below.

### Accessibility

Accessibility refers to the relationship between patients, the location of services and the time spent travelling 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 travelling to psychiatrists, therapists and support groups due to distance and time spent travelling. Patients frequently estimated travelling times of a minimum of 45 min 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 calibre of doctor. (Patient 3, M, aged 62)

**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 counsellor		10 (76.92)
Currently seeing a mental health specialist		4 (26.67)
Psychiatrist		2 (13.33)
Therapist or counsellor		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)	

ICARE, Improved Cardiovascular Risk Reduction to Enhance Rural Primary Care.

**Table 2** Dimensions of access and patient-reported barriers to mental healthcare

Dimensions	Definition	Subthemes	Patient-reported barriers	Patient-reported facilitators
Accessibility	Services are offered within a reasonable proximity to patient in terms of time and distance.	<ul style="list-style-type: none"> <li>▶ Differences in distance to providers</li> <li>▶ Transportation</li> </ul>	<ul style="list-style-type: none"> <li>▶ Distance to mental health specialists/resources</li> <li>▶ Lack of mobility</li> <li>▶ Severe chronic illness</li> </ul>	<ul style="list-style-type: none"> <li>▶ Local mental health services</li> <li>▶ Social support</li> </ul>
Availability	Services physically exist, are inadequate supply and can meet the volume and needs of the patients served.	<ul style="list-style-type: none"> <li>▶ Identifying brick-and-mortar facilities and workforce</li> </ul>	<ul style="list-style-type: none"> <li>▶ Difficulty establishing long-term relationships with providers</li> <li>▶ Lack of facilities offering mental health services</li> </ul>	<ul style="list-style-type: none"> <li>▶ Dedicated mental health facilities</li> <li>▶ PCP manages mental healthcare</li> </ul>
Affordability	Cost to consumer and the financial viability of service provider. Includes payment from multiple funding streams.	<ul style="list-style-type: none"> <li>▶ Insurance policy for mental health services and treatments</li> <li>▶ Out-of-pocket cost</li> </ul>	<ul style="list-style-type: none"> <li>▶ Lack of mental health parity</li> <li>▶ Pharmaceuticals not covered</li> <li>▶ High co-pays</li> </ul>	<ul style="list-style-type: none"> <li>▶ Complete and ongoing coverage for services</li> </ul>
Accommodation	Clinic operations are organised such that patients can utilise services easily; services are easy and convenient to obtain and use.	<ul style="list-style-type: none"> <li>▶ Communication with the patient</li> <li>▶ Processes for initiating and changing treatment</li> </ul>	<ul style="list-style-type: none"> <li>▶ Communication channel incompatible with patient</li> <li>▶ Waiting lists/waiting times</li> <li>▶ Crisis care unavailable</li> <li>▶ Difficulty receiving referrals</li> </ul>	<ul style="list-style-type: none"> <li>▶ Routine screening and monitoring procedures</li> <li>▶ PCP makes referral to a specific mental health provider</li> </ul>
Acceptability	Patient attitudes about the personal and practice characteristics of a provider or qualities of a healthcare service.	<ul style="list-style-type: none"> <li>▶ Quality of the patient-provider relationship</li> <li>▶ Quality of the healthcare service</li> </ul>	<ul style="list-style-type: none"> <li>▶ Provider 'doesn't listen'</li> <li>▶ Disruption of long-term clinical relationships</li> <li>▶ Unpleasant medication side-effects</li> </ul>	<ul style="list-style-type: none"> <li>▶ Non-judgmental listening</li> <li>▶ Joint decision-making</li> <li>▶ Minimal medication side-effects</li> </ul>
Awareness	Patients can identify that some form of services exist, can be reached, and have an impact on the health of the individual.	<ul style="list-style-type: none"> <li>▶ Mental health literacy</li> <li>▶ Understanding of the mental health system</li> </ul>	<ul style="list-style-type: none"> <li>▶ Inability to locate resources</li> <li>▶ Poor health literacy</li> <li>▶ Poor knowledge of mental health system</li> </ul>	<ul style="list-style-type: none"> <li>▶ PCP educates patient on diagnoses, treatments and options</li> </ul>

PCP, primary care physician.

### Transportation

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

In contrast, facilitators that enabled patients to obtain mental health services were having providers and mental health workforce practicing locally, having a PCP with expertise in treating mental health concerns and having friends or family to take them to their 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.

### Identifying brick-and-mortar facilities and workforce

During the course of the ICARE study, and prior to these interviews, the governor privatised 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 specialised mental healthcare 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)

In contrast to the aforementioned barriers, facilitators to availability included the PCP having special training or expertise in psychiatry, and the clinic having in-house mental health specialists.

### Affordability

Affordability refers to the ability for healthcare services to be reimbursed through different funding streams.

### Out-of-pocket cost

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. Although receiving some types of mental healthcare 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)

### Insurance policy for mental health services and treatments

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 subsidised insurance. The recent changes in Iowa's privatised Medicaid system left some patients with gaps in their mental healthcare coverage after one managed care organisation dropped out of the programme, 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)

Factors that made receiving mental healthcare more affordable was having insurance policies that enabled mental health parity for services. While not personally experienced by patients, some expressed a desire for more low-cost and community-based mental health programmes 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 organisational 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 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 specialised mental healthcare. Many patients were uncertain about where to receive additional or specialised 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 specialised 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 favour 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 upcoming 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 vice 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

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 healthcare; 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 healthcare 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)

#### Quality of the healthcare service

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 counselling 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 healthcare.

#### Understanding of the mental health system

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)

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)

### Mental health literacy

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 firsthand. For instance, many patients reported that they first learnt about anxiety or depression after they had been diagnosed with the condition. In some cases, patients learnt about these conditions from family and friends with similar experiences, who then told them how to seek care.

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 overlapping 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 privatisation of Medicaid and the state-wide shift towards community-based mental health services, which changed the distribution and delivery of services compared with 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<sup>35</sup> and may be more important than other factors, such as distance to services, for rural patients.<sup>36</sup> The present study suggests that shared decision-making between the patient and provider, as well as clinical organisation, 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<sup>23 37</sup>; 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 utilisation 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,<sup>38</sup> 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 utilisation by rural individuals demonstrate how stigma affects the acceptability of services,<sup>39</sup> 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 travelling 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. Thus, utilising multiple pathways to deliver mental health services either locally or remotely may be especially important for rural individuals with limited mobility. Likewise, 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. It should be noted that as our study was restricted to patients over the age of 50, the barrier of awareness (such as the ability to use internet searches) could be contributed to participants' age rather than chronic illness or rural status. Nevertheless the relative invisibility of



mental health services reported by this sample may be an important finding for providers and public health practitioners who wish to promote local services. Overall, 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,<sup>40 41</sup> healthcare utilisation<sup>41 42</sup> and diagnosis rates,<sup>43 44</sup> which has been well-documented in other studies. Further, the barriers to access experienced by Iowans of other racial and ethnic backgrounds may not be represented in these findings, indicating a need to research the experiences of racial and ethnic minorities obtaining rural mental healthcare, specifically. Second, while small sample sizes are often used in qualitative work due to the volume of data generated in qualitative analysis, 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. Further, given the low response rate, it is possible that our findings contain selection bias, and as such the experiences represented here differ considerably from the general population. Further, we note that while all patients met ICARE criteria for inclusion, not all endorsed having a history of mental health diagnosis; this may reflect different levels of mental health literacy or understandings of mental health topics and concepts in this rural older population.

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 geographical sampling within the state and within multiple hospital and clinical 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 analytical framework of a modified theory of access from Penchansky and Thomas allowed us to account for and characterise 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 behaviours, understanding of the diversity of healthcare settings and provider types and critical organisational 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.

**Contributors** LEP and KK conceived and designed the study. BLC was the principal investigator who designed and conducted the original ICARE study from which this

sample was obtained. LEP and KK participated in the recruitment of the subjects for this substudy. LEP and KK participated in the collection, analysis and interpretation of data. LEP drafted the manuscript. KK and BLC critically reviewed and approved this manuscript for publication. LEP revised the manuscript after its initial review.

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