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“you’re Not Gonna Get Any Help, No Matter How Hard You Try” A Qualitative Analysis Of “severity” As A Barrier To Mental Health Care

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“You’re not gonna get any help, no matter how hard you try”

A Qualitative Analysis of “Severity” as a Barrier to Mental Health Care

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Abstract

Objectives: This qualitative analysis explores how severity of need influences how patients perceive, experience and navigate mental health care.

Methods: Participants are English-speaking adults aged 18-64 with private insurance who have severe mental illness (SMI). After gauging interest in participating in telephone interviews, the principle investigators sampled those that used an out-of-network mental health provider (n=8), in-network mental health provider (n=8) and oversampled those that tried to use a mental health provider but ultimately didn't (n=14). The 30 participants were interviewed for ~30 minutes each using semi-structured interview guides. All coding took place within Dedoose version 8.2.32.

Findings: "Severity" emerged and was perpetuated through individual interactions with providers and structural barriers. Participants expressed repeatedly advocating for treatment and having their symptoms normalized (mainly by their PCP). They not only internalized these minimizing consultations but also expressed seeking future care beyond the healthcare system, if at all. Scarcity of providers and burdensome costs of care also reinforced "Severity" by making treatment inaccessible through availability, affordability or both. Due to these barriers, participants identified the emergency room and hospitalization as crucial agents in expediting access to treatment. While these sites were successful in addressing immediate needs and sometimes even catalyzing long term care, it was clear that early opposed to emergent intervention was participants' preference.

Recommendations: Based on participant narratives, the following actions are recommended.

(1) Mental health capacity should be built within primary care in order to increase PCP mental health competence and in turn, lessen patient self-advocacy burdens. This would also profoundly relieve scarcity issues.

(2) Insurance payers should increase reimbursements for in and out of network mental health providers in order to garner in network participation and mitigate out of network costs.

(3) The development of behavioral health specific emergent care options should be supported in order to provide more appropriate and timely care for high need patients.

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Table of Contents

Introduction

Global surveys show familiarity with mental illness and the benefits of treatment has improved in recent years.[1] However, a troubling treatment gap still remains. For example, when considering the United States, 47.6 million adults live with mental illness yet less than half received treatment in 2018.[2] Upon unpacking the aforementioned gap, the literature highlights significantly greater barriers to mental health care in comparison to physical health care.[3] These barriers commonly operate as either an individual level attitudinal factor or system level structural factor.[4]

This study explores the barrier of "Severity"—a patient perception that one can only get mental health care if symptoms are severe. Participants described "Severity" in the following ways: (1) a "qualifying event" must be present to attain sufficient care and (2) our current mental health care system is not preventative. Due to a lack of evidence documenting how severity of need influences how patients perceive, experience and navigate mental health care, this study was conducted. The use of qualitative methodology uniquely captures detailed patient lived experiences with barriers to care. These narratives are critical to making effective and equitable public health interventions.

Background

According to global surveys, familiarity with mental illness and the benefits of treatment has improved in recent years.[1] However, a troubling treatment gap still remains. For example, when considering the United States, 47.6 million adults live with mental illness yet less than half received treatment in 2018.[2] Upon unpacking the aforementioned gap, the literature highlights significantly greater barriers to mental health care in comparison to physical health care.[3] These barriers commonly operate as either an individual level attitudinal factor or system level structural factor.[4] As later defined, attitudinal factors are shown to be particularly relevant for mild-moderate cases while structural factors dominate within severe cases.[5] However, theoretical models of help-seeking behavior call upon the mutually dependent relationship between the two factors throughout a patient's decision-making process.[1]

Due to the lack of a universal health care system, insurance status plays a formative role in accessing mental health care in the United States.[1] In fact, within patients with severe mental illness (SMI), mental health care utilization rates are highest for the publicly and privately insured, and lowest for the uninsured.[6] Perhaps then it is unsurprising that uninsured individuals have higher odds of reporting unmet mental health needs.[7] Despite relative greater access to mental health care for the privately insured, considerable barriers still remain.

Structural barriers are defined as the "objectifiable factors associated with health services."[1] For the privately insured, these barriers commonly look like high rates of denials of care by insurers and high out-of-pocket costs.[8] Cost is particularly important as adults have increasingly reported it as a burden over the past two decades.[9] The literature also identifies difficulty in receiving psychiatric medications and finding adequate mental health providers in network as pressing issues.[8] When considering scarcity, adults note it as specific to mental health

professionals in comparison to other specialists or primary care providers. Scarcity also persists across geography; however, less populated rural areas are particularly vulnerable.[8]

Attitudinal barriers are defined as "cognitions and emotions surrounding help-seeking."[1] These barriers are most commonly reported within the privately insured when compared to publicly insured and uninsured individuals.[7] Additionally, they are particularly critical to how adults initially engage in and continue their mental health treatment. Within those with SMI, the breadth of attitudinal barriers includes adults "wanting to handle their illness on their own", believing their "problem was not severe", trusting they "would get better" and perceiving treatment as ineffective.[5] Stigma is relatively less concerning for adults with SMI.

In 2018, of the 11.4 million U.S adults experiencing SMI, over 4 million did not receive treatment.[2] Additionally, the majority of the U.S population currently gains coverage through a private insurer. The intersection of these realities highlights a significant knowledge gap. In particular, a qualitative analysis of barriers to mental health care for help seeking privately insured adults with SMI is lacking. Furthermore, understandings of how severity of need manifests within the realm of mental health is scarce. This study addresses the aforementioned dearth of evidence by exploring how the barrier "Severity" arises from and interacts with system level structural barriers.

Methods

Study Design & Sample Size

Participants were initially recruited in August 2018 through KnowledgePanel—a high quality online panel of 50,000+ households—to complete an internet survey assessing barriers to in network mental health care. Upon completion, participants were asked if they wanted to take part in telephone interviews. Ultimately, 30 participants enrolled in ~30 minutes interviews facilitated by semi-structured interview guides (Appendix). One of the principle investigators (KK) conducted all 30 interviews which were also recorded. After a professional service completed transcription, the interviews were reviewed for accuracy and deidentified.

Study Population

Participants are English-speaking adults aged 18-64 with private (commercial) insurance who have severe mental illness (SMI). According to the National Institute of Mental Health, SMI is defined as a "mental, behavioral, or emotional disorder" leading to functional impairments that substantially alter one's ability to complete everyday tasks.[10] The principle investigators sampled those that used an out-of-network mental health provider (n=8), in-network mental health provider (n=8) and oversampled those that tried to use a mental health provider but ultimately didn't (n=14).

Participants in the oversampled "tried" category responded yes to the following survey question: *In the last 12 months, did you try to make an appointment with a mental health provider?* "Try" was defined as calling at least one mental health provider or clinic, contacting your insurer or looking on your insurer website for a provider.

Mental health provider is defined as a professional trained to address emotional or mental health problems. These professionals include psychiatrists, therapists, psychologists, mental health nurse practitioners and social workers.

Data Analysis & Software

The coding team separately conducted open coding on three interviews at a time. The team then met weekly to discuss the three interviews assigned and began categorizing experiences as promoters or barriers to care. This structure became more detailed as all the interviews were initially coded and ultimately resulted in a comprehensive codebook.

The final codebook, consisting of 40+ parent and child codes, was then applied to all 30 interviews. During this round of coding, two coders analyzed each interview and reached consensus on codes through weekly meetings. The majority decision on a code was used to resolve any disagreements. The coding team comprised of two MPH research assistants—including the first author—and the principle investigator (KK).

This analysis focuses on two key themes—"Severity" and "Urgency". These codes tell a rich narrative of how interactions with structural factors can create barriers to care. The "Severity" code captured patient perceptions that one can only access services if debilitating mental health symptoms are being experienced. Consequently, the "Urgency" code included patient perceptions that the severity of their mental health expedites their access to care. As demonstrated, the definitions greatly overlap and, in turn, capture similar and relevant patient narratives. Lastly, all coding took place within Dedoose version 8.2.32—a qualitative analysis software.

Findings

1. Perceptions of "Severity"

Participants expressed challenges in accessing mental health care when their symptoms were not severe. By moving through participant narratives of help seeking, we begin to understand how interactions with the system—including structural barriers—amount to the barrier of "Severity". When sharing their experience getting care for their daughter, Participant 2 noted,

"She started refusing to come home…she was clearly an emotional wreck. Didn't get any counseling through the school. Didn't get any counseling through the doctor's office. I needed some help. Help, you know. Then she started cutting and at that point where she started cutting, then they're like, "Oh, now you qualify." That's a qualifying event. There's no preventative mental health. It's clearly crossed the line, now you have a qualifying event. Apparently, you have to be suicidal or you have to cut yourself or you have to lay down on the railroad tracks. Because of her attempted suicide, she got into Kaiser. She got a great therapist."

The quote above captures the fundamental perceptions participants shared: that a "qualifying event" must be present to attain sufficient care and our current mental health care system does not operate through a lens of prevention. Participant 2 also mentioned they had been seeking care for almost three years. Other participants also described their journey advocating for mental health care and highlighted the role of individual providers. As Participant 26 discussed,

"Well, I mean, I've gone through depression before. They just said, well, how are you doing? I just said, I've been really depressed, and having nightmares and stuff. They told me, "Well, that's normal." Which, I guess at the time—I mean, it was my second one. I kind of felt put out, like, okay, but I don't like feeling this way. But in their eyes it wasn't bad enough, I guess. That's the feeling that I got. It wasn't bad enough for them to do anything about it."

By normalizing patients' expressed symptoms, providers failed to meet pleas for support in a timely manner. Among participants, this resulted in not only a lack of engagement in care but also feelings of "dehumanization". As Participant 31 shared,

"…the primary care physician treated me like it wasn't important. He did try to give me some medication, but I got the impression that if I didn't have a severed limb or something, it was a

silly problem. It was just really dehumanizing, and it just emphasized there's really no help at all. You're not gonna get any help, no matter how hard you try, you're not gonna get any help."

These provider interactions, mainly with one's primary care provider (PCP), made a lasting impact on patient perceptions of self and their symptoms. In fact, Participant 2 noted that after repeatedly being disregarded when sharing their obsessive suicidal thoughts, they began to tell themselves, *"Tough it out. Pick yourself by your bootstraps and move along".* Additionally, below, Participant 4 describes how their experience seeking care informed their future help seeking plans.

"I think if ever anything else [besides physical health concerns], I just prefer a youth center. It's not a big deal, but mental health—I think you need to have a severe problem for there to be—for them to request you—get you services. You know what I mean?"

Participants illustrated how delayed care or denial of care can create a ripple effect. In fact, their narratives suggest the lack of early intervention had serious personal consequences including homelessness and separation. Participant 31 delves into this reality below.

"I've had this problem for ten years…and sometimes the problems were severe, they were really severe, and it's gotten so bad. I mean, I've been married for 34 years and my husband left me two months ago, 'cause he couldn't deal with my mood swings. I mean, I lost my job. I'd had a job for nine years, I lost my job because of crying and screaming. I'd start crying and screaming at people at work."

2. Structural Barriers: Scarcity of Providers & Cost of Care

Scarcity of providers and *cost of care* are the structural barriers participants highlighted throughout their descriptions of "Severity". Although the aforementioned barriers are not an exhaustive list of contributing structural factors, they are the most referenced and detailed by participants. Additionally, as a theme across the data set, here, participants made explicit calls for mental health to be treated equivalent to physical health by the system.

Scarcity of both in and out of network providers directly reinforced "Severity" as the shortage of expertise made the care itself inaccessible. To quote Participant 18, *"there's just not enough people to help, and listen"* thus supporting the perception that *"you just get triaged…there's always somebody with more need"*. Participants recounted traveling far distances for adequate care and also never hearing back from provider offices. Stemming from a lack of specialists, wait times were regularly reported as a source of frustration with 2-3-month queues being common. Additionally, adjacent to the literature, scarcity was found across differently populated places including rural and urban regions. As Participant 11 detailed,

"There's really no one there, and if you find one, and you can possibly get in, it's months and months. It's ridiculous and that's just for that first initial. Then it's another month before you can come back and meet with the actual doctor. When you need mental health care, you need it now. You need it right away.

Just like when you got a cold and you go to the doctor; you need to be cared for right away. It's not something that can wait. As far as the actual psychiatrists, there's hardly any in our area. The few that are, are totally overwhelmed, I think. They don't have room to see anybody else."

Cost primarily emerged as a structural barrier due to insufficient insurance coverage and the abovementioned lack of in network providers. Participants spoke to the interconnectedness of structural barriers and ultimately feeling trapped in the cycle of navigating affordability and availability. As Participant 24 summarized,

"I was told that as part of the ACA, your insurance has to provide mental health care, but my insurance—I guess the in-network options are very limited. They claim that they satisfy their requirement by paying for in-patient mental health care if you are a threat to yourself or others.

There is a dearth of options in terms of people that charge a reasonable rate and people that have availability and will accept insurance at all. My primary care doctor put together a list of people for me, and the rates were just too expensive. Then I just have the lack of availability, because they—some of them won't accept new patients for months. Some of them will only see you at off hours. Just the rates and everything were extremely high for even the lowest of them."

While some participants delayed treatment, others expressed the financial toll of going out of network for the sake of receiving timely care. This was a financial undertaking Participant 11 described as necessary for their suicidal child since *"a therapist who is wonderful…is very hard to find."* Like scarcity, by actively making mental health care inaccessible, cost prohibited patients from early intervention. Lastly, a free initial mental health consultation was repeatedly recommended as a measure for insurance companies to implement. As Participant 24 captured,

"There's also this focus on preventative care, but only on like we'll pay for your physical and all the stuff. I feel like if you said, like every plan should have one free, or one fully covered therapy session per year for everybody. They wouldn't have to use it, but I feel—like a physical. Maybe it's something that people should do."

3. Emergency Room & Hospitalization

Participants identified the emergency room and hospitalization as mechanisms that expedite one's access to mental health services. As established, whether it be through interactions with providers or structural barriers embedded in the system, participants are often not deemed severe enough for treatment. In turn, within this study, the ER and hospitalization not only met immediate mental health needs but also aligned participants with satisfactory long-term care. In reference to their child, Participant 11 reported, *"being admitted to the hospital, he found a therapist who was wonderful, which is very hard to find."*. They elaborated with,

"When you're in the hospital, it's actually a lot easier to get in cause they won't let you out of the hospital until you have an appointment. That's actually easier, but if you're just somebody that's trying to make an appointment on your own, forget it. It's much, much harder to get in."

Participant 12 similarly only received adequate care (medication) after the *"first time [they] went into partial hospitalization"*. Despite emergency services perhaps easing the path for some, it is clear that they were used as last resort measures opposed to preferred avenues for

treatment. Patient fatigue and how barriers inevitably exacerbate one other were particularly salient in this section. In context of a loved one, Participant 2 expressed,

"She had finally got on Medi-CAL and they had mental health, but it's in another county and we have no transportation. The waiting list is two months. She tried to get mental health services while being sober and couldn't get mental health services. She went to the emergency room twice. She also does heroin, so she had a relapse and still couldn't get services."

Moreover, Participant 18 narrated the following when speaking to facilitating care for their child.

"Well, you call to try to get an appointment, and you're three to four months out. So, you go into the ER, and then they'll admit you. She attempted five times before she actually killed herself. We brought her home after one of her attempts, and she wanted us to put her in a day treatment program, but all of the programs were for addicts. She wasn't addicted to anything at that point.

You can only do so much. I mean, I have reached the point where, I mean, everybody dies. I mean, it's a sad thing that my daughter died. But I look at it like, you know, everybody dies."

Discussion

As theoretical models explain, individuals move through a series of steps when deciding whether to seek mental health care. This process includes the onset of symptoms, evaluating one's severity, assessing treatment feasibility and ultimately, accessing care or not.[4] As this study suggests, questioning one's severity is not exclusive to initial help-seeking behaviors. Instead, individuals are continually forced to reassess the severity of their symptoms because of the myriad of factors presented in the findings. In summary, due to the larger health care system requiring a threshold level of severity, help seeking individuals are often unable to receive treatment. This creates the patient perception that one can only get care if symptoms are debilitating. Otherwise referenced as "Severity" throughout this study.

The findings suggest "Severity" emerged and was perpetuated through individual interactions with providers and structural barriers. Participants expressed repeatedly advocating for treatment and having their symptoms normalized (mainly by their PCP). They not only internalized this disregard but also expressed seeking future care beyond the healthcare system (ex. youth centers), if at all. Scarcity of providers and cost of care also reinforced "Severity" by making treatment inaccessible through availability, affordability or both.

Due to the aforementioned barriers, participants identified the emergency room and hospitalization as crucial agents in expediting access to treatment. While these sites were successful in addressing immediate needs and sometimes even catalyzing long term care, it was clear that early opposed to emergent intervention was participants' preference. Lastly, we were reminded of the stakes of this work as patients noted homelessness, unemployment and the deterioration of family ties as some of the devastating consequences affiliated with delayed or denied mental health care.

Limitations

Certain limitations should be considered when evaluating this study. Multiple participant quotes used in this analysis were given on behalf of another individual—particularly caregivers in reference to their child. While these caregivers were often responsible for the facilitation of their child's care, it is important to note that the individual with SMI did not directly contribute to the narrative. Furthermore, as the literature supports, access to mental health care can vary greatly based on an individual's social identities—specifically one's race/ethnicity and socioeconomic status. While all study participants were privately insured, consideration of demographics could have provided nuanced understandings of barriers to care.

Despite the presented limitations, this work contributes meaningful patient perceptions of rationing care—an evolving topic of study. Additionally, the study population including individuals who tried to access services along with those who ultimately did is particularly significant as these subpopulations have rarely been studied in conjunction.

Recommendations

Building mental health capacity within primary care would serve as an umbrella agent of change. With the majority of physician visits being to PCPs, these providers are front line responders to mental health crises despite reporting they feel unequipped to handle severe cases.[11] This is supported by evidence showing patients are less likely to meet mental health "treatment thresholds" during PCP visits compared to specialist visits.[12] Investment in primary care would increase PCP mental health competence and in turn, lessen patient self-advocacy burdens. It would also profoundly relieve scarcity issues repeatedly detailed in this study.

Participants also called upon the baseline high cost of in network care and the financial toll of going out of network due to scarcity of providers. Currently, under commercial insurance, mental health providers are incentivized to provide care based on reimbursement amount. This is because certain services are reimbursed less in network while others are greater out of network. For this reason, payers should adopt increased reimbursements across in and out of network care in order to garner in network participation and mitigate exorbitant out of network costs.[13]

Reliance on emergency services in alleviating dire mental health needs was clear in this study. However, institutionally, emergency care is not equipped to handle such cases due to expertise shortage and the sheer influx of high need patients. In response to these realities, initiatives such as telepsychiatry mark a rise in behavioral health specific emergent care. With one in eight ER visits being a behavioral health case, investment in these efforts is evident.[14]

Lastly, as the literature emphasizes, structural and attitudinal barriers are both crucial components to a patient's help seeking behaviors. For this reason, alongside the recommendations outlined above, expansion of culturally competent public education and awareness campaigns regarding mental illness and treatment should be prioritized.[7]

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Appendix

Interview Guide: *For Those that Used Mental Health Out-of-Network*

1. This purpose of this study is to better understand how people choose a mental health provider and how their insurance might impact their decision. Can you tell me about when you used an in-network mental health provider in the last 12 months and how you chose this provider?
    - Potential probe: Tell me a bit more about your reason for using this OON provider.
    - What role, if any, did your type of insurance coverage for mental health play in this decision?
2. Tell me about your experience trying to find a mental health provider.
    - What made this process difficult?
3. What were the financial consequences to you of using an out-of-network provider? Were there any other consequences to you from this experience?
4. Did you consider using an in-network provider? If yes: Why didn't you?
5. Why do you think your out-of-network provider does not take your insurance?
6. Did you ever have a mental health provider leave your network? Can you tell me more about it? If so, how did this impact your mental health or treatment, if at all?
7. Did you ever complain to your insurer or a government agency about difficulties accessing mental health care? If Yes, can you tell me more about your experience?

Interview Guide: *For Those that Used Mental Health In-Network*

1. This purpose of this study is to better understand how people choose a mental health provider and how their insurance might impact their decision. Can you tell me about when you used an in-network mental health provider in the last 12 months and how you chose this provider?

- Potential probe: Tell me a bit more about your reason for using this provider.
- What role, if any, did your type of insurance coverage for mental health play in this decision?

2. Did you consider using an out-of-network provider? If yes: Why didn't you?
3. Tell me about your experience trying to find a mental health provider.
   - What made this process difficult?
4. Did you ever have a mental health provider leave your network? If so, how did this impact your mental health or treatment, if at all?
5. Did you ever complain to your insurer or a government agency about difficulties accessing mental health care? If Yes, can you tell me more about your experience?

Interview Guide: *For Those that Tried to Obtain Mental Health Care, but Ultimately Didn't*

1. Can you tell me about when you tried to use a mental health provider in the last 12 months?
2. What do you think ended up being the main reason you didn't obtain care?
   - Did your insurance coverage ever factor in to why you did not obtain care?
   - Did you ever experience difficulties finding a mental health provider? If Yes, can you tell me more about it?
3. Were there any consequences to you from this experience?
4. Did you ever have a mental health provider leave your network? If so, how did this impact your mental health or treatment, if at all?
5. Did you ever complain to your insurer or a government agency about difficulties accessing mental health care? If Yes, can you tell me more about your experience?