Utilizing a CBPR approach to assess the impact of COVID-19 on individuals who receive publicly funded behavioral health services

Nickholas Grant1 | Ronald Byrd2 | Robert Forlano2 | Steven Olsen2 | Richard Youins2 | Michael J. Sernyak3 | Doreen Fulara1 | Joy S. Kaufman1

1Department of Psychiatry, Division of Prevention and Community Research, Yale University School of Medicine, Yale University, New Haven, Connecticut, USA
2The Consultation Center, New Haven, Connecticut, USA
3Department of Psychiatry, Yale University School of Medicine, New Haven, Connecticut, USA

Correspondence
Joy S. Kaufman, Department of Psychiatry, Division of Prevention and Community Research, Yale University School of Medicine, 389 Whitney Ave, New Haven, CT 06511, USA. Email: joy.kaufman@yale.edu

Abstract
The coronavirus disease pandemic has highlighted significant gaps in community mental health services, placing vulnerable individuals at greater risk for mental health and substance use difficulties via disrupting their wellness journey. Guided by a wellness framework, a needs assessment was conducted among adult consumers of behavioral health services to understand their needs during the pandemic and to help develop and strengthen service delivery strategies. A team of three university researchers and four Consumer Researchers, who receive services at a publicly funded community mental health center, engaged in a community-based participatory project in which 13 focus groups were conducted with 51 consumers. Several themes emerged from a thematic analysis of transcripts regarding consumer well-being and healthcare needs, coping strategies employed, and the accessibility, benefits, and perception of clinical and support services during the pandemic. Results highlighted strengths in service delivery and areas in need of enhancement. Findings may inform similar community services that seek to enhance delivery of care among vulnerable populations.

KEYWORDS
action research, community-based participatory research, Consumer Researcher, COVID-19, mental health services, pandemic, vulnerable populations
According to the World Health Organization (WHO), mental health providers in various countries are experiencing significant disruption in services since the onset of the The coronavirus disease 2019 (COVID-19) pandemic (WHO, 2020). For instance, WHO reported that community-based outpatient services, mental health prevention and promotion programs, school-based mental health services, suicide prevention programs, community outreach services, medication managements services, and inpatient services for substance use disorders have either been completely or partially disrupted during the pandemic. Subsequently, this disruption in service array has highlighted significant gaps in community mental health services, which has placed many vulnerable individuals at greater risk for mental health and substance use difficulties (Kahl & Correll, 2020).

Based on data from the Center for Disease Control and Prevention (CDC), the COVID-19 pandemic has been associated with significant increases in anxiety and depressive disorders, substance use, trauma-and-stress related disorders connected to the pandemic, and reports of suicidal ideation (Czeisler et al., 2020). According to Rains et al. (2021) qualitative synthesis of various sources (i.e., peer reviewed journal articles, published first person accounts, media articles, and publications by governments, charities and professional associations), other consequences include increased loneliness and social isolation, lack of access to services and community resources, and social adversity (e.g., domestic violence and job loss). For example, Czeisler et al. (2020) assessment of the impact of the COVID-19 virus in the United State in June 2019 found that anxiety and depression rates increased three and four times (i.e., 25.5% vs. 8.1% and 24.3% vs. 6.5%, respectively) when reassessed a year later. Of note, prevalence rates were significantly higher among racial and ethnic minorities, young adults (ages 18 – 24), essential workers, self-reported unpaid caregivers, and those with preexisting psychiatric conditions. This trend indicates that the COVID-19 pandemic has had a disproportionate impact on specific populations that are vulnerable and in need of more support and consideration in future policy and care procedure development.

1.1 | SAMHSA' eight dimensions of wellness

Researchers have particularly called attention to the ways in which the COVID-19 pandemic can exacerbate preexisting mental health and substance use challenges and subsequently increase individual’s vulnerability and risk status (Cullen et al., 2020; Melamed et al., 2020; Sheridan Rain et al., 2021). One way to characterize the impact COVID-19 has had is through a wellness framework. Specifically, the Substance Abuse and Mental Health Services Administration (SAMHSA, 2016) created a multidimensional model of wellness that includes eight dimensions: (a) Emotional, (b) Environmental, (c) Financial, (d) Intellectual, (e) Occupational, (f) Physical, (g) Social, and (h) Spiritual wellness. These dimensions indicate goals, preferences, interests, and strengths of individuals as well as provides a framework to help individuals think about ways to boost their quality of life, in light of persistent challenges (Swarbrick, 2006). Utilizing these core dimensions when understanding individuals’ experiences with the pandemic could provide insight into the myriad ways consumers of behavioral health services have been impacted.

Melamed et al. (2020) illustrate one example of how the pandemic has impacted dimensions of individual wellness. For instance, with individuals with substance use challenges, they found that (a) the lack of infection control in social spaces increased their exposure (e.g., when procuring substances (both recreational and illicit substances and with using substances via hand-to-mouth exposure in common space) (b) there were social consequences with being disproportionately impacted by housing, food, and financial insecurity and increased risk with utilizing community services, such that shelters and food banks were over crowded; and (c) there was increased risk for respiratory infection given the impact substances have on the immune and respiratory systems. These concerns are coupled with the finding that the fear and worry related to the pandemic is associated with increased substance use coping motives (Rogers et al., 2020)—all of which can arguably impact multiple dimensions
of one's wellness. Similar vulnerabilities have been noted among individuals with psychotic disorders (Kozloff et al., 2020) and Alzheimer’s Disease and related dementias (Brown et al., 2020).

In addition to individual impact, the COVID-19 pandemic has had an impact on healthcare systems. Health providers and programs are now tasked with understanding the needs of the individuals they serve and developing strategies to strengthen and enhance service delivery now, and in preparation for future crises. Many services in the beginning of the pandemic transitioned to alternative treatment methods including teletherapy via telephone or video conferencing (most common) and helplines to maintain social distancing and safety (Czeisler et al., 2020). Individuals with preexisting mental health and substance use conditions have also reported relying on self-management strategies (e.g., journaling, exercise, meditating, maintaining a positive outlook, and other leisure activities), social support and peer networks, social media, and community/online support (Raines et al., 2021). However, the feasibility and efficacy of telehealth methods in treating mental health and substance use disorders is still under research in the context of pandemic related restraints. In addition, there are still issues of equity that create challenges for individuals seeking remote treatment, such as having access to quality technology and internet services (Connolly et al., 2020; Rains et al., 2021). Lastly, the literature regarding the resources and supports needed by consumers of mental health and substance use services is still under research in the context of pandemic related restraints. In addition, there are still issues of equity that create challenges for individuals seeking remote treatment, such as having access to quality technology and internet services (Connolly et al., 2020; Rains et al., 2021). Lastly, the literature regarding the resources and supports needed by consumers of mental health and substance use services is still in its infancy. Raines et al. (2021) review provides some data on individuals experiences during the pandemic as well as highlighting that there has been little empirical investigation, especially from the perspective of consumers of mental health and substance use services. As such, we assert that it is vital that mental health professionals and providers cocreate future programming and services in collaboration with consumers of their services to build greater sensitivity to consumer identified needs and circumstances—especially as in-person services begin to reopen. To do so, we utilized a community-based participatory research (CBPR) approach to develop a more nuanced understanding of the experience of individuals with mental health and substance use challenges during the COVID pandemic.

1.2 CBPR

CBPR projects are empowerment-based, grassroots approaches that engage community members, organizational representatives, and researchers in systematic research to enhance their lives and communities (Israel et al., 2005). According to Israel et al. (2005), CBPR is a mutually beneficial partnership in which each member involved are given equal power in constructing the research process, especially given their expertise and lived experiences with regard to the topic under investigation. Ideally, the goal of CBPR projects is to leverage the strength and resources of a community in each phase of the research process, including (a) creating and integrating research and action by which individuals identify research questions, learn to assess and develop research tools, and practice data collection and analysis; (b) promoting critical thinking, collaboration, knowledge generation, and capacity building among all partners; (c) disseminating results to all partners; and (d) developing possible recommendations and action steps to influence rules and policies that help build long-term sustainability within the community (Israel et al., 2005). Through implementing CBPR, our goal was to leverage the resources and expertise of all partners to understand the needs of consumers at a public community mental health center during the pandemic.

2 THE CURRENT STUDY

The goal of this project was to understand consumer perspectives of the impact of the COVID-19 pandemic on their well-being and healthcare needs and on current services and supports provided by a publicly funded community mental health center during the COVID-19 pandemic. Specifically, we had several research aims, including to understand: (a) how the COVID-19 pandemic affected their lives, (b) strategies they employed to cope during the pandemic, (c) whether their physical and mental healthcare needs were met, (d) whether there were any
unmet needs and resources they require, (e) what kind of services and/or supports have they gotten from the center since COVID began, and (f) how not being as connected to the center impacted them. The goal was to identify recommendations that would help build the center's capacity and infrastructure as well as support consumers in the short- and long-term in event future crises should arise.

3 | METHODS

3.1 | Community setting

This study was conducted in an urban publicly funded community mental health center that provides recovery-oriented mental health services. The center services over 5000 consumers each year who suffer from severe and persistent psychosis, depression, anxiety, and various addictions challenges (such as alcohol, substance use, and gambling) and comorbid conditions. The center also offers outreach programming for consumers who are homeless, at serious risk for mental illness, and/or involved with the criminal justice system. In addition, the center offers rehabilitation programming to help improve daily functioning and quality of life.

3.2 | Consumer Research Project

The Consumer Research Project is an ongoing quality improvement effort at the center that has been determined to be exempt by Human Research Protection Program. Since 2013, multiple Consumer Researchers have been recruited and trained—given their expert knowledge as recipients of services—in effort to assess other consumers' perceptions of the community mental health center's services and care environment. Consumer Researchers were trained by a university team to (a) lead focus groups, (b) develop questions and coding schemes, (c) analyze focus group data, (d) disseminate findings to the center leadership, and (e) make recommendations for improvement.

The research team includes three university researchers, one of which identifies as a Black male and the others identify has White women. The Consumer Researchers included two self-identifying Black men and two White men. Additionally, we worked closely with our community partners at the center over the course of the study, including one White man who is the center’s director and one Black woman who is the center’s director of clinical services, who helped coordinate project tasks.

In line with CBPR, each phase of the research process was co-constructed through continuous reflection and discussions of project related tasks to promote multiple perspectives and reflexivity. This philosophy aligns with social constructivism which states that research strategies should be guided by four principles in which researchers: (a) acknowledge one's positionality, privileges, perspectives, and interactions with the participants shape data collection and analysis, (b) practice reflexivity by thinking through what and how they are doing things and why, which may require (c) improvising ones' methods and data analysis strategies throughout the research process; and (d) collect rich data to seek and define hidden meaning within a cultural and social context—all for the purpose of being critical, constructive, and considerate when interpreting how research participants construct their world. Throughout the research process, the research team engaged in discussions in which we openly discussed and kept note that our perspectives and research agenda was influenced by our roles, as partners and/or consumers of services at the center.

3.3 | Participants

A convenience sampling approach was used to recruit individuals for the focus groups. Specifically, members of the research team approached consumers who receive services from the center’s money management and treatment and
support groups and asked if they were willing to participate in a focus group. In addition, groups were held at group homes, congregate care settings, and social support group meetings. Finally, two groups were held virtually including one with consumers who are deaf and hard of hearing. In total the team conducted 13 focus groups which included 51 consumers.

3.4  |  Methodological integrity

Methodological integrity as described by Levitt et al. (2017) is the methodological foundation of trustworthiness, was of paramount importance to ensure credibility and validity of findings and rigor throughout the research process. Integrity is accomplished when the research design and procedures (e.g., sampling and data collection and analysis) support the research goals (i.e., utility of methods) and respects and reflects fundamental characteristics of the subject matter and investigators to achieve authenticity within the process (i.e., fidelity of subject matter; Levitt et al., 2017). We met these criteria through implementing the following strategies: (a) members of the research team and those we recruited as participants were consumers of behavioral health services, which provides a more representative sample of those seeking services at a local community mental health center, (b) the research agenda was defined, informed, and lead by the Consumer Researchers given their expertise and lived experiences with mental and substance use services, (c) data analysis of focus group transcripts were conducted separately and then discussed collectively as a group to triangulate findings from data sources (i.e., focus group transcripts).

3.5  |  Research procedure

At the request of mental health center leadership in the summer of 2020, the Consumer Research team was tasked with understanding the impact of the COVID-19 on consumer’s well-being and of their perception of care during the pandemic. First, the team developed the research procedure and protocol. This included weekly meetings to develop a plan to recruit potential participants that would maximize safety for all parties involved, such as hosting focus groups in open spaced areas or on zoom. In addition, the team identified questions that would help gauge consumers well-being, healthcare needs, and perception of care during the pandemic. Questions were informed by SAMHSA’s Dimensions of Wellness and were developed and refined through continuous dialog among Consumer Researchers, the research team, and community partners on areas of need and concern that were particularly relevant to the experiences of consumers of mental health services (see Table 1). Consumer Researchers and the team collectively drafted questions until there was consensus among the group and verified and approved by our community partners. Consumers were then invited to participate in the groups. Participation in focus groups was limited to six participants per group, everyone wore masks, and groups were held outside to adhere to COVID-19 safety guidelines. All focus groups were audiotaped to ensure accuracy and then transcribed verbatim. Identifying information (e.g., name and clinician name) was removed during transcription. Before starting each group, the Consumer Researchers reviewed an information sheet which outlined the purpose of the focus groups and information on confidentiality and participant rights. Focus group participants received a copy of the information sheet. Participants also received a $10 stipend for involvement in a focus group.

3.6  |  Data analysis

Once the audiotapes of the focus groups were transcribed, Consumer Researchers and the academic partners met to develop a coding scheme. Using this coding scheme, each focus group transcript was coded by one Consumer Researcher and one member of the evaluation team. Differences in coding were resolved by a different member of the evaluation team. Data were analyzed using standard procedures for analyzing qualitative focus group data
| Main question                                                                 | Follow-up questions                                                                 |
|------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| How has the COVID pandemic affected your life?                               | How has COVID affected the social aspect of your life?                                |
|                                                                              | How has COVID affected the financial aspect of your life?                            |
|                                                                              | How has COVID affected your mental health?                                            |
|                                                                              | How has COVID affected your physical health?                                          |
|                                                                              | Have you or a member of your family had COVID?                                        |
| What types of things are you doing to help you cope?                         | Have you been able to exercise?                                                      |
|                                                                              | How have you been able to attend to your spirituality or prayer?                      |
|                                                                              | Have you been meditating?                                                            |
|                                                                              | What about connecting with family or friends?                                        |
|                                                                              | What else are you doing to help you to cope?                                         |
| Some people cope in ways that may not be as healthy.                         | Have you been using food to cope, like overeating?                                    |
|                                                                              | What about using alcohol or drugs more than you did before COVID?                    |
|                                                                              | Have you been staying more isolated?                                                 |
|                                                                              | What about sleeping all of the time or not able to sleep?                            |
|                                                                              | Have you been buying more things?                                                    |
|                                                                              | Is there anything else you have done to cope during COVID that may not be as healthy?|
| What types of things do you need that you do not have?                       | Do you have enough food?                                                             |
|                                                                              | Have you had enough money to get what you need?                                      |
|                                                                              | Have you had a safe place to live?                                                   |
|                                                                              | Do you have access to the transportation you need?                                   |
|                                                                              | Do you have the clothing you need?                                                   |
|                                                                              | Have you been able to get masks, or other personal protection?                       |
|                                                                              | What about cleaning supplies?                                                       |
|                                                                              | Have you been able to get support from others?                                       |
| Have you been able to talk to your clinician or doctor since COVID began?    | Did they reach out to you or did you have to reach out to them?                      |
|                                                                              | How long was it before you were able to talk to them?                                |
|                                                                              | How often do you talk to your clinician?                                             |
|                                                                              | Are you able to talk to your doctor when you need to?                                |
| What other ways were you connected to the center before COVID that you no longer have access to? | N/A                                                                                  |
Braun and Clarke (2006) identified six steps in the thematic coding process, which includes familiarizing yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a final report. As such, Consumer Researchers created initial open codes of the focus group transcripts. Consumer Researchers then engaged in a second round of analysis and compared their codes among each other to revise and recategorize them into larger themes. As a group, the team discussed the essence of each theme and then generated a final list of themes after further revision. Only comments made across different focus groups or by consensus of one group of participants were included in the coding. Thus, not everything said in the interviews are included in this summary.

## RESULTS

The research team identified six themes from the focus group data related to: (1) the impact of the COVID-19 pandemic on consumer well-being; (2) strategies that consumers have employed to cope; (3) healthcare needs and access to care; (4) the accessibility of and communication with clinical and support services; (5) the perceived benefits of the mental health services and supports delivered during the pandemic; and (6) desired changes in how the center responded and delivered care during the pandemic. Below, we provide a descriptive summary for each theme. Table 2 provides a more condensed summary of the findings within each theme.

### 4.1 Impact of the COVID-19 pandemic

The first theme included the myriad ways that COVID has impacted the health and well-being (i.e., social, economic, physical, and mental health) of consumers who participated in the focus groups. Specifically, consumers mentioned that feeling isolated from their family and friends, their community and social support groups within the center as one of the biggest impacts of the pandemic. One participant stated, "I miss seeing them...I miss the groups...going to the doctor...talking to people...going to the cafeteria and having a cup a coffee." Unfortunately, about one-quarter of participants stated that they had a close friend or family member who passed away from COVID and expressed sadness and hurt from losing their loved ones so suddenly.

Given the increased isolation and personal and communitywide COVID-related losses, multiple consumers mentioned that their mental health has suffered as a result. Participants reported increased depression and sadness from being alone and mourning their loved ones whom they never got the chance to properly say goodbye to. For example, one participant stated, "Losing my mother devastated me...it was unimaginable and then it happened...I went into a deep depression to the point where I wanted to end my life... because I am always home alone and do not have nobody to talk to." Others reported heightened fear of contracting the virus and dying and feeling anxious about how the future will unfold. Some participants indicated that they have been struggling with their recovery and have relapsed and a few have been hospitalized due exacerbation of their behavioral health issues. All these concerns were stated to be even more difficult to cope with given how disconnected they have been from services and social supports at the center.

Participants also reported that COVID has impacted their physical health, such that some consumers are not able to exercise as much as they desire and are experiencing weight gain. Others indicated they are having difficulty adjusting to wearing mask and are having trouble breathing. For the deaf and hard hearing participants, they mentioned that wearing masks makes it even harder to communicate given that they cannot read others lips or see their facial expressions, both of which are important for social communication. Also, participants stated that they are having financial difficulty in that some reported that they lost their job and are unable to find work and that they are spending more on basic supplies and food due to increased prices. However, it is important to note that about half of participants stated that their financial situation has not changed.
Nonetheless, some participants stated that the pandemic has had a positive influence on their perspective. With some discovering that they are more independent than they had thought and were pleasantly surprised to find that they can live much more independently than expected and were able to utilize strengths that they were not using before. One participant stated, “COVID has affected my life in good, bad, and indifferent [ways]. With social distancing, I had time to think about my life and see who is in control” (Table 2).

4.2 | Coping strategies during the pandemic

A second core theme related to coping strategies applied during the pandemic, which included actions regardless of valence that consumers took to sustain their well-being. When asked how they have been coping during the pandemic, consumers mentioned using a range of coping strategies. Many consumers reported that they were exercising more through walking or biking. In addition, the majority of participants stated that they have been relying on family and friends as a source of support, while a few others mentioned receiving support through virtual church services or from their clinician, doctor, or social groups within the center (e.g., biking group). One participant stated, “For me and my friends...[a social rehabilitation group] encouraged us to exercise... I am just grateful for the group... they made us start off slow [and] I have been going exercising ever since.”

Most participants reported taking precautions to reduce risk of catching COVID because of the significant risk if they are infected. Participants reported wearing masks, maintaining their hygiene and social distancing by avoiding crowds and staying isolated. Other strategies included using technology and media (e.g., music, TV, video games, and social media), journaling, reading, going outside, crafts, mediation, and prayer to maintain a positive attitude and move forward in light of COVID. However, multiple participants reported that they have been smoking significantly more cigarettes and a few people mentioned that their alcohol and/or marijuana use has increased. Several participants indicated that their medications were increased or changed to help them deal with and cope with COVID-related stress. Half of the participants also stated that they have been sleeping more than usual and several reported eating more, given that they are sitting around and not doing much.

4.3 | Healthcare support and basic needs

Healthcare support and basic needs included consumers’ experiences with accessing health and basic care to meet their health and basic needs (i.e., health, housing, financial, and food). About half of the participants stated that they were able to get their healthcare needs met through maintaining their regular check-ups, such as seeing their doctor, dentist, getting a physical, and/or receiving a COVID test. While some participants mentioned that their healthcare needs were not being met, particularly consumers who are deaf or hard of hearing who expressed difficulty with the telehealth technology. They mentioned that the lack of access to an interpreter made it difficult to make appointments and communicate their needs to their doctor. Moreover, almost all of participants indicated that they were able to get their medications, the vast majority expressing that they have continued to take their medication since the beginning of the pandemic. Most specified that they were able to get their medication through visiting nurse support whereas others mentioned they were able to get their medication through a local pharmacy or by having them delivered. Regarding their mental health, less than half of participants stated they have been able to get their needs met. However, some mentioned that they had trouble getting their mental health needs met because they could not get in touch with their clinician or doctor and they did not understand why.

When asked about basic needs, such as access to food, safe housing, transportation, clothing, money, and supplies, consumers responses varied. More than half of the participants reported having access to safe housing, personal protective equipment, transportation, and food. Of special note, multiple participants expressed gratitude for having free access to the bus system at the beginning of the pandemic, which afforded them opportunities to
| Theme                                      | Summary points                                                                                                                                 |
|--------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|
| Impact of the COVID-19 pandemic             | • Increased isolation from family and friends and from social supports within the mental health center.                                         |
|                                            | • Experienced a personal loss from COVID.                                                                                                                                                      |
|                                            | • Increased substance use and depression from being alone and mourning their loved ones.                                                                                                      |
|                                            | • Heightened fear of contracting the virus and dying and about how the future will unfold.                                                                                                     |
|                                            | • Some reported loss of physical activity and financial strain given increased costs of supplies and food.                                                                                       |
| Coping strategies during the pandemic       | • Consumers stated relying on family and friends and peer support groups.                                                                                                                        |
|                                            | • Taking precautions by wearing masks and maintaining their hygiene and social distance to reduce risk.                                                                                           |
|                                            | • Other strategies included staying connected through technology and social media, mediation and prayer to maintain a positive attitude journaling, reading, going outside, and doing crafts at home.   |
|                                            | • Some reported an increase in cigarette use, medication, sleeping, and eating.                                                                                                                                 |
| Healthcare support and basic needs         | • About half reported being able to see their doctor, getting a physical, and/or receiving a COVID test.                                                                                         |
|                                            | • Consumers from the deaf and hard of hearing community expressed difficulty with the telehealth technology and with the lack of access to an interpreter it was difficult to make appointments and communicate their needs. |
|                                            | • Most consumers were able to get their psychiatric medications mainly through visiting nurse support                                                                                         |
|                                            | • About a third of consumers were able to get their mental health needs met.                                                                                                                                 |
|                                            | • More than half had access to safe housing, Personal Protective Equipment (PPE), transportation, and food.                                                                                     |
| Accessibility of and communication with the center’s staff and services | • Consumers reported contact with their clinician by telephone, telehealth, or in person.                                                                                                |
|                                            | • Most reported contacting their clinician every week and to a lesser extent every other week, monthly, or daily, while 27 percent indicated that they could not contact their clinician. |
|                                            | • Some reported receiving no updates from the center about available services or supports.                                                                                                       |
| Helpfulness of center’s services and supports | • Consumers expressed appreciation for continued support services, such as a guidance with money management, online peer support groups that help maintain social connected, the Center’s biking program that gives individuals the opportunity to be active and out in the community through biking, and the Assertive Community Treatment Team which has provided gift cards and care packages that include cleaning supplies and toiletries. |
| Current and desired changes in MHC services | • Consumers appreciated the option to use video conferencing for support groups and to meet with their clinician given that it increased access to services and supports. |
|                                            | • Consumers desired better and more frequent communication (e.g., a warm line, an email/text system, or public service announcements (PSAs)) about the center’s services and reported wanting more online peer support groups. |
complete their errands and travel when needed. However, some participants highlighted that the pandemic has placed a financial strain on them and stated that they did not have enough money for their bills and basic needs. For instance, multiple consumers reported struggling with buying food and supplies (e.g., toilet paper, detergent, bleach, and disinfectant wipes), especially given the rise in prices and need. Some participants mentioned that even having food stamps was not enough to cover food cost and that they had limited access to healthy food options when seeking support through the local food pantries. Several participants also mentioned needing clothes due to the winter season arriving. One participant stated, "I don't have any winter boots, um, and I don't know if I can get any this year. I need like gloves and little stuff, gloves, a couple of pairs of sweatpants, stuff like that would be good."

4.4 Access to and communication with the center's staff and services

Another core theme that emerged were consumers experiences with maintaining connection and access to services at the center. Since the beginning of pandemic, most participants reported that they have been able to contact their clinician on a regular basis. The majority stated that they communicated with their clinician by telephone, a handful reported meeting over Zoom, and a select few mentioned meeting in person off-site. Many reported that they were satisfied with how frequently they touched base with their clinician. However, about a quarter of the participants stated they were having difficulty with getting in touch with their clinicians and expressed confusion as to why they could not see them. One participant stated, "[I tried to] talk to my case manager to help me, but I can't find her, nobody is helping me get in touch with her. Does she work here?" In addition, more than a quarter of participants indicated that they were having trouble getting in touch or have not seen their doctor at all even though they had put in significant effort to try and get in touch with them.

When asked whether they knew what was going on at the center, while many participants mentioned that they were informed, the majority stated that they did not receive any information from the center. If they did receive information, most reported that they got it from their clinician and only a few stated that they got information from the automated message when they called the center. Lastly, multiple consumers mentioned that their clinician had changed during this time, yet they were not notified, which made it difficult for them to connect with their new clinician. One participant stated, "they don't work with me… they don't do nothing for me… I'm not accustomed to that lady and… I'm gonna have to just do it anyway."

4.5 Helpfulness of the center's services and supports

Helpful resources provided by the center that consumers relied on emerged as another core theme, which included services that consumers found most helpful as well as services that they desired yet was discontinued during the pandemic. When asked whether they felt supported during the pandemic, the majority of participants reported that they felt supported by the center. One participant stated, "the center is doing everything they can do while this is going on by giving people masks and telling people to keep their hands clean and to stay six feet apart. They are doing the best they can do." Consumers also expressed appreciation for continued support services, such as a money management which helps provide financial support for food and supplies, online peer support groups that help maintain social connection, the center's biking program that gives individuals the opportunity to be active and out in the community through biking, and the ACT Team which has provided gift cards and special care packages that include cleaning supplies and toiletries. Though not available, consumers also mentioned missing many of the services no longer available from the center, such as the Wellness Center, on-site peer groups, the cafeteria to hangout and chat with friends, social events (e.g., Thanksgiving gathering), the gym, and the recreational activities.
4.6 | Current and desired changes in the center services

Consumers noted multiple preferences for current and desired services that would be helpful during the pandemic, which included the services and supports that would reduce access to service barriers and increase social connection. In terms of current services, many participants mentioned that they appreciated having the option to use Zoom for support groups and to meet with their clinician. A few mentioned that it also helps reduce their travel time and increases their access to services. However, despite wanting to use virtual services, several participants reported that they have difficulty with technology because of the lack of Wi-Fi access and/or not knowing how to use it. It is also important to note that about a quarter of participants stated that they would prefer to meet in person rather than use Zoom because they did not find it helpful. When asked what changes they would like to see at the center some consumers highlighted that they wished there were a hotline to call, with one participant stating, “I wish there was a hotline to call or Zoom meetings with peer support…offer resources…notify us of things that are available…I wish we can get an email or an update of what is planned for the future.” In addition, many consumers reported wanting more online peer support groups. Others reported that providing consumers with more information about available services through an email or a letter would be appreciated. Finally, some reported needing more support to obtain needed supplies and clothing.

5 | DISCUSSION

The purpose of this study was to learn from consumers of publicly funded behavioral health services about their experiences during the pandemic. Utilizing a CBPR approach provided an opportunity to collect data that is viewed as more valid and authentic (Case et al., 2014; Kaufman et al., 2020). The team conducting this study has been working together for the past 9 years to understand different aspect of the care environment at the mental health center. The involvement of the Consumer Researcher team for this study impact at many levels but importantly the team expanded the questions that were asked in the focus groups. While the original request from the mental health center was to ask about access to care, the Consumer Researchers noted in our first meeting to develop the protocol that they knew people who were really struggling and that we needed to expand our protocol to assess all dimensions of health.

Using the SAMHSA Eight Dimensions of Wellness framework, we noted multiple dimensions in which individuals’ wellness have been impacted by the pandemic. Our findings demonstrate that consumers are experiencing significant issues during the COVID-19 pandemic that impact their mental, social, behavioral and physical health, and their basic needs. These individuals are greatly impacted by COVID-related deaths, some have employed maladaptive coping strategies (e.g., increased substance use), many have struggled to receive physical healthcare, and more than a quarter have not connected with their clinician. These barriers to care are exacerbated by limited access to technology for telehealth, which was consistent with previous findings and concerns (Connolly et al., 2020; Rains et al., 2021). Consumers also report struggling to obtain basic needs including food, transportation, and PPE.

Despite these challenges, multiple consumers reported benefiting from continued support services that offset these challenges, such as a guidance with money management, online peer support groups that help maintain social connected, the center’s biking program that gives individuals the opportunity to be active and out in the community through biking, and the ACT Team who provided gift cards and care packages that include cleaning supplies and toiletries. In addition, consumers found positive ways to cope despite being disconnected from services by staying connected through technology and social media, mediation and prayer, journaling, reading, going outside, and doing crafts at home. These results provide more empirical evidence for Rains et al. (2021) findings that self-management strategies and staying connected to one’s social support were key coping mechanisms. Further, the option to use video conferencing for support groups and to meet
with their clinician was perceived as a strength in the center's service delivery given that it increased access to services and supports. In fact, consumers desired more online peer support. Within a wellness lens, one can argue that multiple dimensions of their wellness, such as for example, their social, financial, physical, emotional, and spiritual wellness needs are being met through system (e.g., online programs, money management) and interpersonal and individual level supports.

What was learned in this study was more challenging for our research team than any of our other studies as it was clear that the individuals who receive care at the center were struggling and needed enhanced support. Our team spent considerable time examining the data, processing what we had learned and developing recommendations for the center leadership. The results were so compelling that the Consumer Researchers were asked to present their findings at a center-wide staff meeting.

5.1 Limitations

There are multiple noteworthy limitations to the current study that should be recognized. For instance, there may be some limits to how and to what extent these findings can be generalizable and transferred (i.e., external validity) to other community-based mental health providers. For instance, consumers who participated in the current study identified context-specific resources within their community (e.g., social support groups) that may not be present or obtainable in other communities. Moreover, by using a CBPR approach, the research design procedure reflected the team’s coconstructed interpretation of what was important to ask during the focus group investigation. Given that we used a qualitative research design, we do not know the prevalence rates of these findings and whether and how these findings would reflect in a center wide or national survey study. Lastly, COVID-related restrictions had a significant impact on recruitment. Specifically, focus groups included a convenience sample of consumers coming to the center, living in congregate care or attending social rehabilitation programs. In addition, the size of focus groups was limited for safety. As such, the results may not fully capture the lived experiences of other consumers due to limitations with recruiting individuals in person and potential barriers related to access (e.g., transportation) and exposure.

5.2 Research and practice implications

The results highlighted multiple strengths in the center’s response to the pandemic in connecting with consumers, providing care through phone or telehealth and finding creative ways to offer support. More research is needed to study the benefits of telehealth services on mental health and substance use outcomes—especially the role of online peer support groups which was perceived as highly valuable among consumers. In terms of practice implications, in the analysis of the data there were several recommendations that the Consumer Researchers identified for the center’s leadership to consider implementing during the COVID-19 pandemic and to prepare for any future crises (see Table 3). Recommendations from the data includes ways the center can enhance communication, social services and support, and social connection opportunities for consumers to engage with peers and staff. It is important to note that the center leadership did carefully examine the findings and recommendations from the study conducted by the Consumer Research team and saw the need to act on them. The center recently submitted an application for Federal COVID funds that would allow for implementation of the recommendations made by the Consumer Research team, this application is under review. Finally, these recommendations may inform other publicly funded mental health centers that seek to enhance their delivery of care during this time of crisis.
CONCLUSION

The COVID-19 pandemic has had significant impact on individuals and healthcare systems in the community. Those more impacted included vulnerable individuals who face mental health and substance use difficulties as well as challenges with accessing quality services. Findings from this needs assessment highlighted the impact that the COVID-19 pandemic has had among adult consumers of behavioral health services. However, findings also showed significant strengths in the center’s response and in consumers’ abilities to cope with the ongoing stress of the pandemic. Providers and practitioners of mental health and substance services could use these findings and the recommendations created by consumers to help guide their practice.

DATA AVAILABILITY STATEMENT

The qualitative data were collected as part of an internal quality improvement project and thus is not publicly available.

ORCID

Nickolas Grant  https://orcid.org/0000-0003-0098-7565
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