COVID19 concerns among persons with mental illness

Mark Costa, MD, MPH

Yale University – School of Medicine

Anthony Pavlo, PhD

Yale University – School of Medicine

Graziela Reis, PMTIC, MPH

Yale University – School of Medicine

Katherine Ponte, MBA, CPRP

ForLikeMinds

Larry Davidson, PhD

Yale University – School of Medicine

Highlights

- People with mental illness are very concerned with disruption of services due to the COVID-19 pandemic;
- People with mental illness are feeling isolated and socially disconnected because of the COVID-19 pandemic;
- Social media and text messaging seem to be the best forms to communicate with those with a mental illness who are having difficulty coping with the COVID-19 pandemic.

Abstract (150 words)

Objective: The Coronavirus Disease (COVID-19) pandemic has been recognized as causing a wide variety of behavioral health problems. Society must mitigate this impact by recognizing that coronavirus can trigger people's fears of exacerbation of existing mental illness. A survey about the coronavirus for people with mental illness was developed. *Methods:* Two hundred and fourteen people responded to the survey, of which 193 self-identified as living with a mental illness. *Results:* Almost all participants living with a mental illness (98%) said they had at least one major concern regarding the COVID-19 pandemic, and 72% said they had at least three major concerns. *Discussion:* People living with a mental illness are very concerned with disruption of services, running out of medication, and with social

isolation during this pandemic. Providers and mental health services could address these fears by connecting with people living with mental illness through text messaging and social media.

Introduction

The Coronavirus Disease (COVID-19) pandemic has been recognized as causing a wide variety of behavioral health problems (1). On March 17, a national poll found that 40% of Americans reported life disruption due to the COVID-19 pandemic (2). It has been demonstrated that the impact of quarantine can be long lasting, with substantial psychological impact (3). Social distancing, disruption of services, and unemployment affects vulnerable populations disproportionately (4). In this sense, people with mental illness are more vulnerable not only to COVID-19 infection but also to its behavioral health consequences. Ultimately, people with mental illnesses will be more impacted from social distancing and from disruption of services (5). Society must mitigate this impact by recognizing that coronavirus can trigger people's fears of exacerbation of existing mental illness and by articulating plans that accommodate such people's needs. Ideally these plans should receive input from people with mental illness themselves (4). To this end, an on-line survey was conducted of people with mental illness about COVID-19 and its impact on their wellness by ForLikeMinds, a web site dedicated to promoting mental health recovery and wellness (6).

ForLikeMinds is an online peer support community dedicated to the recovery and wellness of people living with or supporting someone with mental illness, substance use or a stressful life event. Launched in 2018, its founder is living in recovery from serious mental illness. ForLikeMinds has over 12,000 members in addition to a Facebook ForLikeMinds community of nearly 18,000 followers (6). To ask its members and followers about how the COVID-19 pandemic was impacting their lives, ForLikeMinds developed a 11-question survey. The survey asked questions about if respondents self-identify as having a mental illness, diagnosis, concerns with the pandemic, how they were coping with the pandemic, and about social connectedness and loneliness.

ForlikeMinds leadership contacted the XXX XXX XXX XXX XXX XXX XXX to better understand the results of the COVID-19 survey they had developed and submitted to their participants. We hypothesized that the results from the survey developed and conducted by ForLikeMinds could help advance understanding of the impact of the COVID-19 pandemic among people with mental illness. This could potentially help shape interventions specifically designed to minimize the impact of the COVID-19 pandemic on this population.

Methods

A survey about the coronavirus for people with mental illness was developed by ForLikeMinds and distributed on-line to its members and Facebook community. The Survey Monkey platform was utilized to distribute the survey. It was distributed in the last week of March 2020. Responses were voluntary and anonymous. XXXXXXXXXXXX XXXXXXX XXX XXXXX XXX XXXXX XXXXX was contacted to help interpret the results. An Excel spreadsheet with the de-identified data was sent for analysis. SPSS was used to determine frequencies of responses. Cross tabulation was used to establish correlation between nominal variables (such as diagnosis and feeling lonely because of the pandemic). Fisher's exact test was used to determine which correlations were statistically significant. Analysis of Variance was used to

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establish association between nominal variables (e.g. diagnosis) and the absolute number of concerns participants had about the pandemic. For all correlations, significance was determined at the level of $p < 0.05$.

Results

Two hundred and fourteen people responded to the survey, of which 193 self-identified as living with a mental illness. Nineteen percent of all participants and 10% of those living with a mental illness said they supported someone living with a mental illness. Of those living with a mental illness, 84% reported having an anxiety disorder, 53% having major depression, 40% having bipolar disorder, 41% having post-traumatic stress disorder, 13% having obsessive compulsive disorder, 13% having borderline personality disorder, 2% having schizophrenia, and 15% having other disorders. Almost all participants living with a mental illness (98%) said they had at least one major concern regarding the COVID-19 pandemic, and 72% said they had at least three major concerns. Eighty nine percent (89%) of participants living with a mental illness had at least one major concern related to their mental illness and 92% of participants had at least one other major concern not directly related to their mental health care.

Regarding concerns related to their mental illness, 64% of people living with a mental illness were concerned that their mental illness would worsen due to the COVID-19 pandemic. Thirty nine percent were concerned that they would not be able to receive mental health care, and 38% were concerned that they would run out of medication. Regarding other concerns not directly related to their mental health care, 74% of participants living with a mental illness were afraid that someone in their family or themselves were going to get sick with the COVID-19, 30% were afraid of losing income, 23% were afraid of not being able to afford testing and/or treatment for COVID-19, and 18% said they could not afford to shelter in place and miss work. Only 12% of participants thought they were coping well with the pandemic, while 23% said they were coping poorly; 68% felt they were more isolated; and 57% felt they were less socially connected. When asked about who people living with a mental illness were connecting with, 72% said they were connecting with family, 57% with friends, 16% with co-workers, and 14% with peers. The preferred form of communication was text messages (86%) followed by phone (73%), and social media (66%). Altogether, 97% of participants who self-identified as having a mental illness used one of these three forms to communicate.

Concern with their mental illness getting worse was associated with the diagnosis of anxiety ($p = 0.001$), fear of not getting treatment ($p = 0.045$), fear of someone in their family or themselves getting sick ($p = 0.045$), and coping poorly with the pandemic ($p = 0.001$). Fear of running out of medication was associated with diagnosis of major depression ($p = 0.026$), borderline disorder ($p = 0.031$), fear of getting worse ($p = 0.005$), concern with not being able to afford treatment ($p = 0.001$), and with not being able to afford staying home from work ($p = 0.02$).People who self-identified as having anxiety were associated with concern that their caregiver would be unable to support them ($p = 0.045$), concern of not getting treatment ($p = 0.037$), concern of getting sick ($p = 0.026$), and coping poorly ($p = 0.017$). People who self-identified as having major depression were associated with the diagnosis of bipolar disorder ($p < 0.001$), fear of running out of medication ($p = 0.026$), and fear of getting sick ($p = 0.011$), They were also less connected to family ($p = 0.014$). People who self-identified as having borderline personality disorder were associated with concern about not being able to stay home and miss work ($p = 0.006$), concern about not being able to receive mental health treatment ($p = 0.003$), concern with running out of medication ($p = 0.031$), and concern about not being able to care for their loved one

living with mental illness (p = 0.038). People who said they were coping poorly with the COVID-19 pandemic were associated with the self-diagnosis of anxiety (p = 0.017), with concerns of getting worse (p = 0.001), concern of developing a new mental illness (p = 0.039), concern of not getting access to treatment (p = 0.041), concerns that their caregiver would not be able to support them (p = 0.022), feeling isolated (p = 0.033), were less connected to friends (p = 0.019), and were less connected to family (p = 0.001). There was also a negative association between coping poorly with the COVID-19 pandemic and using the phone as a form of staying in touch with people (p < 0.001). Interestingly, no significant associations were found between coping poorly with COVID-19 and using text messages or social media as a form of staying in touch with people.

The Analysis of Variance demonstrated a significant correlation between having an anxiety disorder and number of concerns (p < 0.001).

Discussion

The survey was conducted during the third week of shelter in place recommendations in the East coast of the US. It was not surprising to learn that practically all survey participants living with a mental illness expressed significant concerns with the COVID-19 pandemic and with how it would affect their mental health. People living with a mental illness not only have to deal with all the uncertainty related to the pandemic, but also with the possibility of disruption of the strategies each one has built to support their on-going recovery. Adding to the fear of disruption is the fact that not everyone has a family member or a friend they can count on if needed. Feeling more isolated during the pandemic was very prevalent. More concerning was the fact that almost 60% of participants felt less socially connected when compared to before the COVID-19 pandemic. Those who felt less connected were significantly more concerned about the worsening of their condition and running out of medication. Concerns with the need of working, fear of not being able to afford cost of treatment and not being able to provide and care for loved ones with mental illness were also present.

Self-identified diagnosis was correlated with several variables. It was predictable but important to notice that people who self-identified as diagnosed with anxiety presented most concerns. They were the group, together with post-traumatic stress disorder, that seems to be most affected by COVID-19. We also found a significant correlation between anxiety disorder and coping poorly with COVID-19.

Coping poorly with COVID-19 was of major concern for this population. They felt more isolated, were less connected to family and friends, they were concerned with their treatment, with access to medication, with getting worse and with developing a new mental illness. Specific measures/strategy could be developed to target this population and minimize the impact of the consequences of the COVID-19 pandemic.

What is encouraging is that practically all survey participants said that they were accessible through phones, text messaging and social media. In fact, they are already using these means to minimize social isolation and to remain informed. It is important to notice that people who said they were coping poorly with the consequences of the pandemic were not using their phone as much to communicate and stay in touch with people. In reaching out to this population, providers should consider using text messaging and social media as preferred methods. Virtual platforms can also be an effective way of involving people living with mental illness in building new strategies and solutions to minimize disruption of care.

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