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COVID-19 and the Spinal Cord Injury Community: Concerns About Medical Rationing and Social Isolation

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Purpose/Objective: To provide a descriptive account of the impact of the COVID-19 pandemic on the spinal cord injury (SCI) community focused on participants' concerns about medical discrimination and medical rationing, the impact of the pandemic on access to personal care attendants and medical supplies, and the impact of the pandemic on overall and mental health. **Research Method/Design:** Cross sectional, observational study among community-dwelling adults with SCI. Data were collected online between May 1, 2020 and August 31, 2020 ($n = 187$). The online questionnaire included questions regarding medical discrimination and rationing, the impact of the pandemic on access to care and medical supplies, and the impact of the pandemic on overall and mental health. **Results:** Individuals with SCI have experienced difficulty accessing medical supplies due to the pandemic, and approximately half of our participants (52%) perceived that discrimination through medical rationing was occurring. Furthermore, compared to the general U.S. population, our sample reported that the pandemic had a greater negative impact on their mental health and access to medical supplies. **Conclusion/Implications:** Our findings suggest that the COVID-19 pandemic has negatively impacted mental health and increased concerns of social isolation as well as access to medical supplies among those with SCI. Rehabilitation psychologists must advocate alongside the disability community to limit health disparities and to conduct outreach, specifically with regard to mental health issues. Future research should focus on the effects of pandemic-related fears and social isolation, as well as resilience in the context of public health care threats.

Impact and Implications

People living with spinal cord injury (SCI) are often immunocompromised, and at increased risk of respiratory infection. Therefore, individuals living with SCI may be at risk of health deterioration as a result of COVID-19 and the associated public health restrictions. People living with SCI may also experience compounding stress related to reduced access to medical supplies, and fear of being denied access to care in addition to fear of contracting the virus may contribute to reports of adversely affected mental health during the pandemic. The issues raised in this article highlight the need for rehabilitation psychologists to conduct outreach to patients who may not already have established mental health care and offer a full range of telehealth support and interventions to bridge the gap of mental health care delivery and psychosocial support to those who most need it.

Keywords: spinal cord injury, COVID-19, mental health, medical discrimination, medical rationing

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Data are available from the lead author upon request.

The University of Minnesota Institutional Review board approved this study. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. The authors have no conflicts of interest to disclose.

Kimberley R. Monden was responsible for study design, oversight of data collection, extracting and analyzing data, interpreting results, and writing the article. Erin Andrews was responsible for interpreting results and contributing to the introduction and discussion. Carrie Pilarski was responsible for contributing to the introduction and discussion. Jasmine Hearn was responsible for contributing to the introduction and discussion. Robert Wudlick was responsible for data collection and editing the article. Leslie Morse was responsible for study design, interpreting results, and editing the article.

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Introduction

The rapid rise of COVID-19 cases requiring hospitalization has threatened the capacity of health care systems across the U.S. and around the world. Health care systems have faced critical shortages of life-saving resources, including insufficient numbers of hospital beds, medical staff, personal protective equipment (PPE), and ventilators. In this context, many health care organizations developed strategies to triage and ration medical resources, including mechanical ventilators and ICU beds. With this process there was serious concern that medical rationing would disproportionately impact the disability community (Lund & Ayers, 2020), including individuals with spinal cord injury (SCI). For instance, the American Bar Association highlighted problematic provisions of medical care for disabled people, such as categorical exclusions based on disability, failing to allow longer time on ventilators due to disability status, and authorizing reallocation of ventilators from chronic ventilator users to other patients (Hoogenes et al., 2020). Disability discrimination concerns also have been highlighted by the mainstream media throughout the pandemic (“One Man’s Covid-19 Death,” n.d.; “People With Disabilities Are at a Disadvantage with Covid-19,” 2020).

Early in the pandemic, crisis care standards and triage protocols emerged that were expressly biased against disabled persons. As a result, the Office of Civil Rights in the Department of Health and Human Services (HHS) opened investigations and released a statement warning against possible violations of the Americans with Disabilities Act (ADA; “Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19),” HHS Office for Civil Rights in Action, 2020). Disability activists and medical ethicists advocated for the development of crisis triage protocols that would not unfairly disadvantage disabled people, for example, by focusing on near-term prognosis (Solomon et al., 2020). Health care facilities were also encouraged to adopt a transparent process to reduce bias in decision making (Solomon et al., 2020).

Prior to COVID-19, significant health disparities existed between disabled people and their nondisabled peers, including decreased access to adequate health care services, poorer health outcomes, and experience of stigma and bias in health care settings (Armitage & Nellums, 2020). During the COVID-19 pandemic, concern has been raised about disabled people living in institutional settings who may be more susceptible to contracting the virus because of contact to numerous caregivers (Andrews et al., 2021). For example, research conducted in New York State demonstrated that people with intellectual and developmental disabilities living in residential group homes were at greater risk of severe COVID-19 outcomes, including a significantly higher mortality rate (Landes et al., 2020).

Similarly, individuals who require care in their homes, for example home health care services and personal care attendants (PCAs), may also be at greater risk of exposure due to the inability to self-isolate (Andrews et al., 2021). At the same time, mandatory social distancing policies and “stay at home orders” may be limiting access to essential services for people with disabilities, including access to PCAs and medical supplies. The World Health Organization (WHO) recognized that many disabled people have been disproportionately affected by disruptions to essential services and have experienced difficulty maintaining social distancing

because of the need for additional support in their homes or institutionalization (WHO, 2020). In this way, COVID-19 is positioned to further exacerbate preexisting health disparities adversely affecting the disability community.

Those with SCI face the same difficulties related to COVID-19 as others with disabilities, but also experience challenges related to the nature of SCI. Physiologically, SCI patients can present differently than COVID-19 patients without SCI. For example, due to poikilothermia, or inability to regulate temperature, patients with SCI, especially those with higher injury levels, and COVID-19 may not present with fever (Goetz et al., 2013). This is because cervical and high thoracic SCI can disrupt the neurological signals responsible for temperature regulation, causing vasoconstrictive impairment that prevents the elevation of body temperature in response to inflammation or infection (Dicks et al., 2020). Another possible diagnostic confound is that presence of fever in SCI patients may be misattributed to urinary tract infection (UTI), a common occurrence in the SCI population and a frequent cause of fever (Korupolu et al., 2020). Massa and colleagues (2009) found that fever had very high specificity for diagnosing UTI, but very low sensitivity, indicating that while individuals with SCI and UTI almost always present with fever, the presence of fever often indicates a diagnosis other than UTI in those with SCI. Those with SCI, especially those with tetraplegia, may have an atypical presentation of respiratory illness, if the ability to cough and clear secretions is affected by SCI-related muscle weakening (Dicks et al., 2020). Similarly, reduced lung capacity can occur in SCI as a result of muscle weakness, making viral pneumonia both more likely and more difficult to detect (Korupolu et al., 2020). For these reasons, people with SCI who contract COVID-19 are at risk of misdiagnosis, delayed diagnosis, and potentially more severe complications from the virus, which could be critical in terms of access to lifesaving interventions. Already the emerging literature suggests that the COVID-19 mortality rate for those with SCI is higher than for those without SCI (Hoogenes et al., 2020).

The purpose of the present study is to provide a descriptive account of the impact of the COVID-19 pandemic on the SCI community. Specifically, this article describes participants’ concerns about medical discrimination and medical rationing, the impact of the pandemic on access to personal care attendants (PCAs) and medical supplies, and the impact of the pandemic on overall and mental health.

Method

This study reports observational, cross-sectional findings derived from baseline data reported from a larger longitudinal study examining the impact of the pandemic on individuals with SCI over time in terms of access to care and medical supplies, impact on overall and mental health, and activities and participation. Data are collected online using REDCap at five timepoints: baseline (spring to summer 2020) and 3, 6, 9, and 12 months. Data for this analysis were collected between May 1, 2020 and August 31, 2020. The University of Minnesota Institutional Review Board approved this study. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

Participants

Participants were recruited internationally through distribution of recruitment materials to various SCI stakeholder groups, including the North American Spinal Cord Injury Consortium, the Paralyzed Veterans of America, the United Spinal Association, the International Spinal Cord Society, FacingDisability.com, and the European Spinal Cord Injury Federation. Participants were also recruited through social media channels, including Twitter and Facebook, and existing research registries. Participants included in the study had a diagnosis of SCI or disorder through self-report, were 18 years or older, and were able to comprehend English.

Measures

Medical Rationing and Discrimination

Participants were asked three questions related to medical rationing and discrimination: (1) If you are hospitalized during the COVID-19 pandemic and need a ventilator, are you concerned that you will not get one due to your SCI? (yes/no); (2) In the past three months, do you believe medical discrimination in the form of medical rationing is currently taking place where you live? (yes/no); and (3) If you are now or in the future diagnosed with COVID-19, how fearful are you that you will not receive appropriate medical care (e.g., access to a ventilator) because of your disability status? (0 [not at all fearful] to 100 [very fearful]).

Impact on Access to Care and Medical Supplies

Participants who indicated they required a PCA or nurse were asked to rate the impact of the pandemic on the care they receive in their home on a scale from 1 (*no impact*) to 4 (*major impact*). All participants were asked to rate the impact of the pandemic on their access to medical supplies on a scale from 1 (*no impact*) to 4 (*major impact*) and how concerned they were about access to

medical supplies on a scale from 0 (*not at all concerned*) to 100 (*very concerned*).

Impact on Overall and Mental Health

Participants were asked two questions related to their current health: (1) Compared to before the COVID-19 pandemic, how would you rate your current health? 1 (*much worse*) to 4 (*much better*); and (2) How has the COVID-19 pandemic impacted your overall health? 1 (*no impact*) to 4 (*major impact*). Participants were asked one question related to their mental health: How has the COVID-19 pandemic impacted your mental health? 1 (*no impact*) to 4 (*major impact*).

Social Isolation

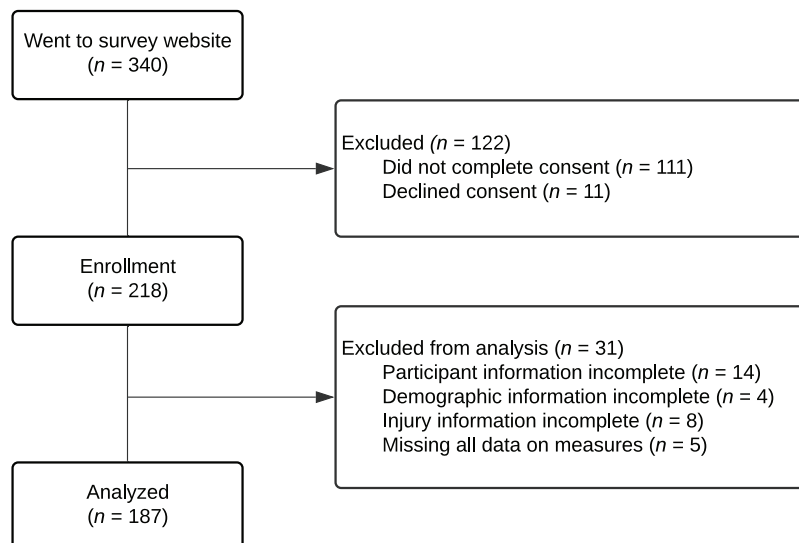
Participants were asked two questions related to social isolation: (1) Right now, how bothered are you about being socially isolated due to the COVID-19 pandemic? and (2) Thinking about the future, how concerned are you about continued social isolation due to the COVID-19 pandemic? Both questions were rated on a scale from 0 (*not concerned at all*) to 100 (*very concerned*)

Results

Participant Sample

The total analytic sample consisted of 187 individuals (see Figure 1) with SCI who were 57 (14.5) years old at the time of the survey. Most of the sample identified as men (74%), White (93%), and resided in private residences (94%) in the United States (87%). The average time since injury was 20.4 (14.9) years and the majority of the sample described their injuries as traumatic (87%) and incomplete (67%). Most of the sample reported having paraplegia (52%). The sample did not include any participants

Figure 1
Enrollment Diagram



who were dependent on mechanical ventilation. Sample demographic and injury-related information are detailed in Table 1.

Medical Rationing and Discrimination

Approximately half of participants (52%) reported that they believed medical discrimination in the form of medical rationing was currently taking place where they lived, and 30% reported concern about being denied access to a ventilator if hospitalized with COVID-19. Participants also reported feeling moderately concerned about being denied access to medical care due to their disability status. Findings are displayed in Table 2.

Impact on Care in the Home and Medical Supplies

Table 3 displays the impact of the pandemic on care received in the home and access to medical supplies. Most participants (60%) reported that the pandemic has had a negative impact on the care

Table 1
Summary of Participant Demographic and Injury Characteristics

Continuous variables	<i>N</i>	<i>M</i>	<i>SD</i>
Age	187	57.0	14.50
Time post injury	171	20.37	14.87
Categorical variables	<i>N</i>	<i>%</i>	
Gender			
Man	138	73.80	
Woman	47	25.13	
Transgender or other related category	2	1.07	
Race			
White	150	92.59	
Black	8	4.90	
Other	4	2.47	
[Missing]	[25]	—	
Country of residence			
United States	161	86.56	
United Kingdom	14	7.53	
Canada	3	1.61	
Netherlands	3	1.61	
Germany	2	1.08	
Ireland	1	0.54	
Switzerland	1	0.54	
Greece	1	0.54	
[Missing]	[1]	—	
Type of residence			
Private residence	176	94.12	
Hospital	1	0.54	
Nursing home/skilled nursing facility	3	1.60	
Assisted living facility	6	3.21	
Other	1	0.54	
Type of injury			
Traumatic	162	86.6	
Nontraumatic	25	13.4	
Injury level			
Paraplegia	91	51.71	
Tetraplegia	85	48.30	
[Missing]	[11]	—	
Completeness of injury			
Complete	54	32.53	
Incomplete	112	67.47	
[Missing]	[21]	—	
Ventilator dependent			
Yes	0	0	
No	100	100	

Table 2
Concerns About Medical Discrimination and Rationing

Categorical variables	<i>N</i>	<i>%</i>	
Concern About Ventilator Denial			
Yes	55	29.73	
No	130	70.27	
[Missing]	[2]	—	
Concern About Medical Discrimination			
Yes	90	52.33	
No	82	47.67	
[Missing]	[15]	—	
Continuous variable	<i>N</i>	<i>M</i>	<i>SD</i>
Fear About Access to Care Due to Disability Status	181	43.80	31.78

they received in their homes. Similarly, 59% of participants reported that the pandemic has negatively impacted their access to medical supplies. Results also show that participants are moderately concerned about access to medical supplies ($M = 39$, $SD = 29$).

Impact on Overall and Mental Health

The impact of the COVID-19 pandemic on overall and mental health is displayed in Table 4. Most participants (68%) reported that the pandemic has had a negative impact on their overall health, and 71% reported a negative impact on their mental health. Additionally, participants reported feeling moderately bothered by social isolation ($M = 52$, $SD = 32$) and more concerned about future social isolation ($M = 61$, $SD = 30$).

Discussion

Results of this study indicate that individuals with SCI have experienced more difficulty accessing medical supplies due to the pandemic than the general U.S. population. Although not a direct comparison to medical supplies in general, a tracking poll by the Kaiser Family Foundation (KFF, 2020) found that only 4% of the general population had been unable to get their prescription medication, while 50% of participants in our sample reported that the pandemic had negatively impacted their ability to access medical supplies. Compared to the general population, the SCI population has a higher likelihood of requiring medical supplies. Therefore, shortages of medical supplies, including PPE, may have disproportionately affected the SCI population and the broader disability community. The WHO has promoted the importance of making medication and medical supplies available in bulk quantities to people with disabilities in order to reduce the frequency with which they need to access public places such as pharmacies (WHO, 2020), and our findings reinforce the importance of this recommendation.

Consistent with reports from the health care industry, over half of our participants perceived that discrimination through medical rationing was occurring. This finding is congruent with concerns from disability rights advocates and many medical ethicists that disabled people are being de-prioritized for care and that unfair approaches to rationing disproportionately affect patients with COVID-19 who are also disabled (Andrews et al., 2021; Lund & Ayers, 2020; Mello et al., 2020; Solomon et al., 2020). A challenge

Table 3
Impact of the COVID-19 Pandemic on Care in the Home and Medical Supplies

Categorical variables	N	%	
Impact on Care Received in the Home (N = 88)			
Yes	53	60.24	
Major impact	5	5.68	
Moderate impact	16	18.18	
Minor impact	32	36.36	
No	35	39.77	
Impact on Access to Medical Supplies			
Yes	108	58.70	
Major Impact	9	4.89	
Moderate Impact	39	21.20	
Minor Impact	60	32.61	
No	76	41.30	
[Missing]	[3]	—	
Continuous Variables	N	M	SD
Concern About Access to Medical Supplies	178	39.49	28.95
Bothered by Social Isolation	178	52.64	31.69
Concern About Future Social Isolation	177	61.02	30.29

also exists that health care systems may view individuals considered to be at a higher risk as being “protected” by reducing in-person visits for routine care while also potentially placing them at a higher risk due to a general reduction in care (e.g., through lack of access to physiotherapy). Furthermore, a component of the surveyed participants expressed moderate concern about being denied access to life-sustaining medical care, including access to a ventilator, due to their disability status. Although no participants in this study used a ventilator in their daily lives as part of their stable disability functioning, early in the pandemic some crisis care standards called for reallocating these personal ventilators to other patients upon a disabled patient’s presentation to acute care hospitals (Mello et al., 2020). Thus, such fears are not unfounded even as expressed by those not currently utilizing personal ventilators. In addition to the specific concerns and policies related to medical rationing and ventilators, news related to medical discrimination based on disability status impacting COVID-19 care has highlighted quality of life evaluations negatively impacting the broad community of individuals with disabilities as well as situations specifically including those with SCI (“One Man’s Covid-19 Death,” n.d.; “People with Disabilities Are at a Disadvantage with Covid-19,” 2020).

Compared to the general U.S. population, our sample reported that the pandemic had a greater negative impact on their mental health. The KFF poll conducted in mid-March 2020 showed that 32% of Americans believed the pandemic had affected their mental health, and 14% reported it had a “major impact” (Hamel et al., 2020). By early April 2020, the percentage of respondents who reported the pandemic had affected their mental health rose to 45%, with 19% reporting it had a “major impact.” (“KFF Health Tracking Poll—Early April 2020,” KFF, 2020) In our sample, 71% of participants reported the pandemic had impacted their mental health, with 46% reporting it had a “major” or “moderate” impact. The compounding stress for individuals with SCI related to reduced access to medical supplies and fear of being denied access to care in addition to fear of contracting the virus may

contribute to these reports of adversely affected mental health during the pandemic. So too could social isolation; pre-COVID research suggests that disabled people including those with SCI are more vulnerable to social isolation (Robinson-Whelen et al., 2016) and that social relationships are important to overall mental and emotional well-being for those with physical disabilities including SCI (Tough et al., 2017). Perceived isolation, or loneliness, has been associated with social disconnectedness, which is likely to be heightened during the pandemic given reduced days away from home and frequency of engagement in social activities (Newman et al., 2016). Lund and colleagues (2020) point out that disabled people may experience increased social grief and emotional distress during the pandemic, as a result of their own fears as well as the likelihood of multiple social losses.

Meta-analysis of studies on the relationship between social isolation and health consistently link social isolation and loneliness to worse cardiovascular and mental health outcomes (Leigh-Hunt et al., 2017). In a study of the impact of social isolation on leisure and physical activities among people with SCI, researchers found that loneliness, social network structure, and household size were correlated with time spent engaging in leisure and physical activities (Santino et al., 2020). This preexisting knowledge has implications for the alterations in social connectedness that have occurred during the pandemic and highlight the synergy between physical and mental health.

Although this is a descriptive account of the experiences of individuals during the COVID-19 pandemic, the importance of specifically exploring the experiences of those with SCI recognizes the uniqueness of SCI experiences as it intersects with reduced services or access limitations in the context of the pandemic. Individuals with SCI are at increased risk for exposure to COVID-19, misdiagnosis, or delayed diagnosis, and have higher risks associated with COVID-19 due to the physiology of their SCI. Furthermore, the results highlight several concerns in the SCI community regarding beliefs of discrimination, medical rationing, reduced

Table 4
Impact of the COVID-19 Pandemic on Overall and Mental Health

Categorical variables	N	%	
Current Health Compared to Before COVID-19 Pandemic			
Better	24	12.83	
Much better	7	3.74	
Somewhat better	17	9.09	
Same	115	61.50	
Worse	48	25.67	
Somewhat worse	37	19.79	
Much worse	11	5.88	
Impact on Overall Health			
Yes	127	67.91	
Major impact	23	12.30	
Moderate impact	45	24.06	
Minor impact	59	31.55	
No	60	32.08	
Impact on Mental Health			
Yes	133	71.12	
Major impact	28	14.97	
Moderate impact	58	31.02	
Minor impact	47	25.13	
No	54	28.88	

home services and access to supplies, and decreased overall and mental health. Current and future concerns about social isolation likely intersect with existing challenges that result in compounding stress for those with SCI. The findings from this descriptive study provide insight into the unique and current needs of individuals with SCI during the COVID-19 pandemic.

Limitations

This study is purely descriptive and captures only a snapshot of the experiences of participants with SCI during a four-month period of the COVID-19 pandemic. Continued research is needed to monitor adjustment and concerns as the pandemic continues.

The findings of this study represent the experiences of a large sample and show the negative impact of the pandemic on the overall, subjective well-being of people with SCI. However, the results are based on a primarily White, male sample of people living in private residences in the U.S. As such, the findings should be interpreted as largely reflective of this demographic. Further work is required to establish the extent to which the findings reported in the present study converge or diverge in other demographics. Future studies should also examine the demographic characteristics of individuals who are experiencing the greatest impacts on mental and physical well-being, which will be necessary to prioritize resources for the SCI population. Although the present study provides some indication of the impact of the COVID-19 pandemic on individuals with SCI, further information is required to examine which aspects of the pandemic and protective measures have the greatest impact and why. This information will ensure that interventions to support people with SCI are targeted with effective and timely use of resources (in an already resource strained environment). Finally, due to the cross-sectional nature of this observational study, causal inferences cannot be made.

Conclusion

These data raise an alarm bell for medical professionals who serve patients with SCI and other disabilities. Fears about being denied access to routine care and life-sustaining care during medical rationing are well-founded and affecting those we treat. It is important for patients with SCI to be aware that COVID-19 may present differently in the context of their injuries and become familiar with civil rights legislation that demands that patients cannot be categorically excluded from access to treatment because of a disability (Mello et al., 2020). However, the onus must not be solely on patients and their support system to advocate, particularly when social distancing and isolation within acute care settings limit access to visitors. One approach to increase advocacy for the SCI population is to embrace interdisciplinary care and involve rehabilitation psychologists early in the care of SCI patients with COVID-19.

The WHO has released a guide for action that can be taken by disabled people, caregivers, health care providers, disability service providers, and governments to mitigate the devastating impact of COVID-19 on the disability community (WHO, 2020). The American Psychological Association “advocates for the rights of people with disabilities, including policies that prevent discrimination and provide access to needed services and care” (American

Psychological Association, n.d.). As such, rehabilitation psychologists have a duty to advocate within their communities and health care systems for transparent and fair crisis care guidelines and triage protocols that do not unfairly discriminate against disabled people. Rehabilitation psychologists can also advocate for bulk provision of medical supplies to disabled patients, promote full accessibility of testing and services related to COVID-19, ensure that communications about COVID-19 are fully accessible to the disability community, coordinate support for those with the most complex needs, and educate other health care professionals about the heightened risk that COVID-19 poses to the disability community.

In terms of mental health, future research should investigate the extent to which pandemic-related fears and social isolation play a role in mental health status. Research is also needed on resilience and factors promoting positive mental health in the face of global issues with medical and health care threats. Future research should also explore the unique challenges posed by the pandemic, such as the impact of virtual delivery of rehabilitation interventions and potential differences in effectiveness of telehealth platforms versus telephone-only interventions for individuals without high-speed internet access. Finally, the impact of increased risk and vulnerability of many individuals with SCI who require care in their homes, and the concomitant stresses on caregivers, also warrants future examination.

For now, rehabilitation psychologists can conduct outreach to patients who may not already have established mental health care and offer a full range of telehealth support and interventions. Highly accessible mobile applications can also be particularly useful with this population to provide psychoeducational information or supplement treatment. For example, the Veterans Health Administration released COVID Coach, a free and secure app with evidence-informed tools for stress management, health and safety tips, and a mood tracker (Jaworski et al., 2021). Telephone, apps, text messaging, and video conferencing can all help bridge the gap of mental health care delivery and psychosocial support to those who most need it.

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