REVIEW

Exploring the Mental Health Needs of Persons With Autoimmune Diseases During the Coronavirus Disease 2019 Pandemic: A Proposed Framework for Future Research and Clinical Care

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Although the coronavirus disease 2019 (COVID-19) pandemic has been associated with increased psychological distress globally, it poses unique challenges to persons who are potentially more vulnerable to its effects, including patients with autoimmune disease. In this article, we review the published literature and media reports to determine factors that may contribute to mental health challenges in persons with autoimmune disease. We then explore existing mental health interventions that have been developed for use in COVID-19 and in patients with autoimmune disorders in general. We identified several potential contributors to psychological distress in patients with autoimmune disease during the pandemic, as follows: feelings of discrimination related to societal response to COVID-19, fear of infection and uncertainty related to immunosuppressive medication, diminished access to usual care and resources, previous health-related trauma, and the exacerbating effect of social isolation. Drawing from existing literature, we synthesize the identified evidence to develop a proposed framework for researching and managing mental health challenges in autoimmune disease during the pandemic and its aftermath.

INTRODUCTION

In addition to the illness-specific burden of coronavirus disease 2019 (COVID-19), the pandemic has been found to be associated with high levels of psychological distress. A survey conducted of the general population in China following the outbreak identified that of 1210 respondents, 53.8% rated the psychological impact of the pandemic as being moderate or severe, reporting symptoms of depression, anxiety, and stress (1). In addition to other clinical and demographic factors, poor self-rated health status was associated with higher psychological distress.

Thus, although devastating at a global level, COVID-19 presents unique challenges to people living with chronic illness such as autoimmune disease, particularly with regard to mental health. Autoimmune disease increases vulnerability to depression and

other mental health challenges in general for biological, psychological, and social reasons (2-8). Individuals living with autoimmune disease may be more vulnerable to mental health difficulties during COVID-19 because of factors related directly to the pandemic and its associated social effects, factors related to their autoimmune disease, and societal factors. Conversely, many people living with chronic disease have developed coping strategies over their illness course that may assist with managing COVID-19–related stress, both from a psychological and instrumental perspective.

Although papers have been published regarding clinical management of autoimmune disease during the COVID-19 pandemic (9) and although it has been speculated that persons with immune dysfunction are at risk of mental health challenges during the pandemic (10), little attention has been paid thus far to factors that may contribute to mental health challenges of patients

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with autoimmune disease in the setting of COVID-19. Elucidating these factors will allow clinicians, researchers, and patients with autoimmune diseases to develop strategies to manage mental health challenges during the COVID-19 pandemic and its aftermath. Thus, the aims of this paper are to *1*) describe the existing evidence regarding the effect of the COVID-19 pandemic on mental health in patients with autoimmune disease, *2*) discuss factors that may contribute to mental health in persons with autoimmune disorders, *3*) explore existing mental health interventions that have been developed for use in COVID-19 and in patients with autoimmune disorders in general, and *4*) synthesize the identified evidence to develop a proposed framework for researching and managing mental health challenges in autoimmune disease during the pandemic and its aftermath. This article relies on the published literature for evidence when available, but given the limited research in this area and the evolving situation, we have also drawn from the grey literature, primarily media reports.

MATERIALS AND METHODS

We used a narrative review framework for this manuscript (11). The first author (KSB) conducted three searches to identify *1*) peer-reviewed articles and grey literature relevant to mental health and autoimmune disease during the COVID-19 pandemic, *2*) peer-reviewed articles relevant to mental health generally during the COVID-19 pandemic and during previous pandemics, and *3*) randomized controlled trials regarding mental health interventions in autoimmune disease in general. The primary database used to capture peer-reviewed publications was PubMed, complemented by a Google search to identify relevant articles and sources from the grey literature for articles relevant to mental health in persons with autoimmune disease and chronic illness during COVID-19. We modified search terms used in a review of chronic illness and COVID-19 by the Centre for Evidence-Based Medicine (12). Bibliographies were searched for additional potentially relevant articles. In addition, we searched the resources listed

on the American Autoimmune Related Diseases Association, Inc, website (https://www.aarda.org/aarda-covid-19/) to investigate resources compiled specifically for the autoimmune disease community, and we searched ClinicalTrials.gov for registered clinical trials investigating mental health interventions or related studies regarding management of patients with autoimmune disease during the COVID-19 pandemic. The initial searches were done in April 2020 and updated on September 16, 2020. Search terms are shown in Table 1.

Mental health challenges in patients with autoimmune disease during COVID-19: published literature. In a cross-sectional study comparing survey responses in May 2020 from 134 patients systemic lupus erythematosus (SLE) in Poland with those from a control group of 589 people without SLE but with other chronic diseases (eg, hypertension and diabetes), Wankowicz et al showed that patients with SLE showed significantly more symptoms of anxiety, depression, and sleep disorders (13). This finding was true even when controlling for age, gender, and chronic disease diagnoses. As a cross-sectional study, these findings are not able to establish a causal link between COVID-19 and mental health challenges in persons with autoimmune disease. However, they support elevated levels of distress in this patient group and the need for further research on this topic. This study did not examine potential contributors to increased distress in persons with SLE.

Ziade et al investigated the impact of COVID-19 on patients with autoimmune disease in 15 Arab countries via a web-based survey of 2163 patients (14). The survey was developed by rheumatologists in the Arab Adult Arthritis Awareness group to specifically assess the impact of COVID-19 on a variety of outcomes, including treatment factors and impacts on personal life, relationships, and mental health. This study found that 73% of participants described a negative impact of COVID-19 on their mental health, with decreased rheumatology visits, medication interruption, decreased access to hydroxychloroquine, use of

Table 1. Search terms

	PubMed	Google	Comment
Search 1	(autoimmune disease OR rheumatic disease OR lupus OR rheumatoid arthritis) AND (mental health OR depression OR anxiety OR stress OR distress) AND (COVID-19[ti] OR COVID[ti] OR coronavirus OR pandemic*[ti] OR epidemic*[ti] OR outbreak*[ti])	("mental health") AND ("COVID" OR "pandemic") AND ("autoimmune disease" OR "rheumatic disease" OR "chronic illness" OR "disability")	PubMed search was sorted by date of publication, from February 2020 to Sept 16, 2020. Google search was conducted in Toronto, Ontario, Canada.
Search 2	(mental health OR depression OR anxiety OR stress OR distress) AND (COVID-19[ti] OR COVID[ti] OR coronavirus[ti] OR pandemic*[ti] OR epidemic*[ti] OR outbreak*[ti])	N/A	Sorted by date of publication
Search 3	(autoimmune disease OR rheumatic disease OR lupus OR rheumatoid arthritis) AND (mental health OR depression OR anxiety) AND (treatment* OR intervention* OR management OR psychotherapy OR psychological treatment* OR cognitive behavior* therapy OR mindfulness) AND (randomized controlled trial OR controlled trial OR RCT OR meta-analysis)	N/A	Sorted by date of publication

COVID-19, coronavirus disease 2019; N/A, not applicable; RCT, randomized controlled trial.

precautions, mask use, isolation, and financial stress, and COVID-19 infection was negatively related to mental health on multivariate analysis.

Elran-Barak and Mozeikov used an online self-report survey to investigate the impact of 1 month of Israeli near-lockdown measures on subjective health, health behaviors, and loneliness in persons with chronic disease (N = 315), including those with autoimmune disease (n = 64 persons with cancer or an autoimmune disease) (15). They found that 50.5% of people reported worsening mental health during the pandemic and, whereas one-third reported feeling lonely before lockdown measures, two-thirds reported loneliness after. Loneliness was a significant contributor to decline in self-reported health. Decline in mental health was found to be associated with female gender, crowded housing conditions, and higher body mass index. Persons with orthopedic or pain conditions were also more likely to report a decline in mental health.

Louvardi et al examined the effect of time spent in quarantine in 163 participants with chronic health conditions (including 37 with autoimmune diseases) on distress, anxiety, depression, and somatization compared with healthy control subjects (16). They found that patients with autoimmune disease exhibited higher levels of somatization (physical symptoms with no clear organic cause, which are often related to psychological distress) than healthy control subjects. They did not find a difference in anxiety and depression scores between patients and control subjects.

An internet-based cross-sectional survey of Turkish patients with rheumatic disease (N = 771) during the first month of the COVID-19 pandemic revealed a relatively high prevalence of anxiety (20%), depression (43%), and post-traumatic stress symptoms (28%) (17). These levels were comparable with those of a comparison group of people working in the academic sector and significantly lower than rates observed in hospital staff. The survey also identified that most patients with rheumatic disease (86%) were not willing to go to the hospital (or were asked to postpone their visits), and 22% stopped their disease-modifying medications or reduced their dose.

Contributors to mental health challenges. Based on the published literature cited above, complemented by evidence from the grey literature (primarily media reports), we summarize potential contributors to mental health challenges in persons with autoimmune disease during the COVID-19 pandemic below.

Societal response to COVID-19. When news of a novel coronavirus reached the media in early 2020, there was substantial uncertainty as to the potential nature and scale of the illness, with some, including political leaders, downplaying the seriousness of the illness, particularly for younger, healthy people (18). The World Health Organization and Centers for Disease Control and Prevention (CDC) provided education on populations at highest risk from COVID-19 infection, mainly persons over the age of 65 years and those of any age with pre-existing medical

conditions (19,20). Social media users took such statements to indicate that authorities were minimizing the risk of COVID-19, indicating that societal fear of the virus is overblown and that "only" older people or those with pre-existing medical conditions need worry (21). According to media reporting, such statements led people living with chronic disease, including autoimmune conditions, to feel devalued and isolated (21).

The downplaying of COVID-19 among healthy people can be conceptualized as a form of social discrimination, whereby the lives of individuals with chronic illness are viewed as less valuable than those of other members of the population. Perceived discrimination is a known correlate of mental health difficulties (22). Furthermore, the tension between relaxing strict physical distancing measures to aid in economic recovery while ensuring adequate protection for people who are vulnerable to serious illness may add to the distress and uncertainty that people with autoimmune disease are experiencing.

Fear of infection and treatment uncertainty. Fear of infection is a normative response to a serious pandemic. However, this response is exacerbated in vulnerable groups, in whom perceived life threat is known to be associated with negative mental health outcomes during epidemics (23). Persons with chronic disease often live with health-related anxiety in general (24), and the threat of COVID-19 infection has the potential to exacerbate this anxiety. According to the CDC, persons taking immunosuppressant medication (such as many patients with autoimmune diseases) might be at increased risk of severe illness from COVID-19 infection (19). Although evidence is emerging regarding the impact of COVID-19 on persons with autoimmune disease, much remains uncertain (9). Autoimmune disease is associated with a higher risk of infection generally, likely because of primary disease-related factors, comorbidities, frequent use of glucocorticoids, and immunosuppressive medications (25). This situation leads to the potential for substantial uncertainty.

Uncertainty is a common feature of chronic illness, and higher levels of uncertainty are associated with increased difficulty coping (26). Although there is no literature specifically regarding the impact of uncertainty on emotional distress and coping in the setting of chronic illness during a pandemic, uncertainty around the circulating disease is known to be associated with psychological distress generally in an epidemic setting (23). Thus, it is not a logical leap to infer that the current heightened uncertainty has the potential to increase distress for patients with autoimmune disease, likely over and above that of the general population. Media reports have highlighted the anxiety that people with autoimmune diseases are experiencing because of COVID-19, with individuals reporting fear of dying from COVID-19 or becoming seriously ill and not fully recovering and describing the stressful uncertainty associated with the current situation (27,28).

Compounding this uncertainty is the potential shortage in disease-modifying medication that patients with rheumatic diseases are facing (29), which was identified by Ziade et al as being

negatively related to mental health in patients with rheumatic disease (14). Despite limited evidence for efficacy and safety from in vitro (30) and small uncontrolled trials (31), many patients with COVID-19 are being prescribing hydroxychloroquine, a medication commonly used for autoimmune diseases such as lupus and rheumatoid arthritis (32). Resulting medication shortages have caused significant anxiety for patients with autoimmune diseases, causing some to report rationing their own supply (33). However more recent, larger studies did not show benefit of hydroxychloroquine in COVID-19 (34,35), leading to the Food and Drug Administration's withdrawal of its emergency use authorization for chloroquine and hydroxychloroquine (36). These developments may reduce the demand for hydroxychloroquine and, hopefully, the associated stress for patients with autoimmune disorders taking this medication.

Reduced access to usual care and resources. Substantial health care resources have been devoted to reducing the burden of COVID-19 on the health care system. In an attempt to increase capacity for patients with COVID-19, particularly those requiring critical care, as well as to reduce the virus' transmission, hospitals canceled nonemergency surgeries, postponed investigations, and canceled clinics. Compounding this issue is the fear associated with seeking emergency care during the COVID-19 pandemic, forcing patients to weigh the risk of morbidity or mortality from a non–COVID-19–related condition against the risk of potentially contracting COVID-19 while seeking care. As discussed in the literature review, Ziade et al described reduced access to usual care as being negatively related to mental health in patients with rheumatic disease (14), and Seyahi et al reported high rates of clinic avoidance in patients with rheumatic disease during the pandemic (17). Additional case reports from the literature indicate that people with potentially serious acute conditions are avoiding seeking care because of fear of exposure to COVID-19 (37). In general, persons with chronic health conditions are known to be at risk for morbidity and mortality during major disruptions to the health care infrastructure, such as times of natural disaster (29).

Fortunately, modern technology has allowed many patients with autoimmune diseases to continue to access care virtually, for instance, via telemedicine. Although this shift is certainly better than being left without care, we do not know the emotional impact that virtual (versus in-person) care has on patients who are receiving treatment for serious illness. This may be particularly true for patients who are being newly diagnosed with a life-altering condition. In general, patients report a variety of emotional responses to receiving bad news, including shock, fear, sadness, acceptance, and confusion (38,39).

Even if the diagnosis is made in person, many patients may be alone without family support because of visitor restrictions. Evidence for best practices in delivering difficult health-related news suggests the importance of an adequate environment, clinicians' awareness of patient's nonverbal cues such as facial expression and body posture, and the provision of support and resources after breaking difficult news (40). Virtual care can affect all of these factors, and evidence suggests that the way difficult diagnoses are initially discussed can have a significant effect on patients' psychological adjustment after receiving bad news (41). Furthermore, many patients benefit from having a support person present when discussing health care decisions generally or when receiving treatment, both for emotional support and to assist in taking in and carrying out ongoing management recommendations. This is particularly true for persons who are vulnerable, such as those with cognitive impairment, psychiatric conditions, or sensory impairments. Time will tell how the COVID-19–related restrictions to chronic care and caregiver support will impact the mental health of persons with autoimmune disease.

Previous health care experience. Serious and critical illness is associated with symptoms of anxiety, depression, and post-traumatic stress (42,43). Evidence from the health psychology literature suggests that patients with serious illness may experience anxiety and distress when exposed to reminders of their illness (44). Such reminders could include experiences such as entering hospitals for appointments, seeing depictions of illness in the media, or experiencing physical symptoms reminiscent of a previous illness experience.

Given this evidence, one might predict that persons who are vulnerable to anxiety and have experience with serious illness, such as some patients with autoimmune disease, might experience heightened distress related to the media coverage of COVID-19 and associated severe illness. This may be particularly true for persons who have previously required hospitalization, which is perceived as a traumatic experience by many patients (45).

Social isolation and quarantine. Social isolation, a consequence of the physical distancing measures enacted in many populations to reduce the burden of COVID-19 on health care systems, is challenging for many people. Quarantine (defined as separation and restriction of movement of those who have potentially been exposed to a contagious disease) (46) may be particularly challenging and has been found to be a predictor of psychological distress during a previous pandemic (23). Quarantine has also previously been found to be specifically associated with emotional disturbance, depression, low mood, stress, insomnia, irritability, post-traumatic stress symptoms, anger, and emotional exhaustion (46).

Researchers in the United Kingdom examined the relationship between psychological factors and a variety of mental health outcomes in the general population during the COVID-19 lockdown from March to May of 2020. They found that the characteristics of psychological flexibility (the ability to recognize and adapt to situational demands) to be associated with greater wellbeing and avoidant coping style (tendency to distract or disengage from stress) to be associated with poorer wellbeing and greater distress during the lockdown (47). In previous pandemics, quarantine has been found to be associated with psychological distress for a number of reasons, including fear of illness, frustration

and boredom, inadequate supplies, inadequate information, and financial stress and stigma (46). Social isolation related to physical distancing additionally has the potential to affect mental health via reduced access to typical social supports and change in daily mental health–promoting routine (eg, sleep and exercise).

Therefore, pandemic-related isolation does not affect all individuals and population groups equally, depending on biological, psychological, and social factors. Persons with autoimmune disease may be particularly isolated from their communities because of the potential for higher-risk infections and the associated need for extra caution. Further, physical distancing requirements have the potential to increase the distress of family members and other close contacts of people who are at higher risk of serious COVID-19 infection. Families and other people who cohabitate may have to make difficult choices about levels of contact in order to protect members who are potentially vulnerable. Further research specific to mental health in persons with autoimmune disease during the pandemic will illuminate these challenges in more detail.

Resiliency and coping. Although COVID-19 will likely have a significant impact on the mental health of many individuals, people with autoimmune disease are often uniquely equipped to deal with COVID-19–related stressors. For instance, people who are immunocompromised typically have developed personal hygiene practices and other infection control strategies to reduce their risk of infection, which they can continue during the pandemic. People who have experienced chronic illness may have had to develop strategies to cope with isolation due to illness or effects of treatment, such as fatigue. For example, online communities provide a source of connection for many people with chronic illness (48). These communities also serve as sites for peer support, peer expertise, self-management strategies (48), and opportunities for advocacy (49). Such communities may be invaluable during the physical distancing associated with COVID-19.

Further, although serious illness has many challenges, some people with chronic or serious illness experience post-traumatic growth, in which struggle with adversity leads to the development of new coping skills, reappraisal of life's priorities, personal development, and increased connection to one's physical self (50). Therefore, from a psychological perspective, previous health-related challenges may actually help some individuals with autoimmune disease to adjust better to major life challenges, such as the COVID-19 pandemic, than those without similar experiences. For example, when external factors such as social events, finances, and political decisions are not in one's control, the ability to focus on and appreciate meaningful priorities in life, such as relationships or current health, is highly valuable.

Evidence for mental health interventions during the COVID-19 pandemic. There is no evidence regarding mental health interventions specific to patients with autoimmune disease during the COVID-19 pandemic. Thus, in order to formulate a clinical and research framework for managing mental health concerns in patients with autoimmune disease during the pandemic, we summarized the literature regarding *1)* mental health interventions during COVID-19 in general and *2)* mental health interventions for patients with autoimmune disease in general.

Existing mental health interventions during COVID-19 pandemic. At this point, there are no targeted interventions developed for persons with autoimmune disease during the pandemic, at least in the published literature. However, this is likely to change in the coming months and years. Thombs et al published a protocol for a randomized controlled trial evaluating the efficacy of recreational activities delivered via videoconference in managing anxiety in persons with scleroderma from a subgroup of the Scleroderma Patient-Centered Intervention Network (51). So et al registered a clinical trial evaluating the impact of telemedicine on a number of outcomes in patients with lupus, including anxiety and depression, on ClinicalTrials.gov (52).

Although they are not yet supported by a robust evidence base, individual autoimmune disease patient groups have developed educational materials and are providing updates online relevant to those living with autoimmune disease, including strategies to manage stress and wellbeing. These resources are compiled on the American Autoimmune-Related Diseases website (https://www.aarda.org/aarda-covid-19/). A number of community mental health and national health agencies have provided access to online education regarding coping strategies for the general population. For example, in the United States, the Substance Abuse and Mental Health Services Administration has a number of educational resources and links regarding response to mental health challenges and crises in the setting of disasters (https://www.samhsa.gov/disaster-preparedness), and the National Alliance on Mental Health has provided a comprehensive guide with strategies to manage COVID-19–related distress and practical resources for those with, for instance, financial challenges or who are at risk of domestic violence (https://www.nami.org/covid-19-guide).

Suggested strategies to manage psychological distress during the COVID-19 pandemic generally involve controlling consumption of stressful media content, maintaining social connections via telephone or virtual means, maintaining a routine that includes good sleep hygiene and physical exercise, practicing mindfulness and relaxation, focusing on factors that are within one's control, and connecting with virtual peer support programs when indicated (eg, for persons with mental health or addiction challenges).

In Germany, a COVID-19–specific stepped-care algorithm has been developed that involves initial contact with provision of accurate information, triage, mental health support from various mental health professionals (via telephone or videoconferencing), and aftercare (53). Systematic research into this and related care pathways will help to illuminate their efficacy and utility.

Based on a systematic review of psychological distress during previous quarantines, Brooks et al made several population-level

suggestions for reducing the distress associated with quarantine, including providing individuals who are quarantined with accurate information in a timely manner, providing general and medical supplies, keeping the quarantine period as short as possible, and having leaders emphasize that quarantine is an altruistic act (46).

General evidence for mental health interventions for individuals with autoimmune disease. Outside of the pandemic, a number of randomized controlled trials have been done regarding psychological management strategies for patients with autoimmune disorders. Findings from controlled clinical trials in SLE suggest that cognitive behavioral therapy (with a focus on stress management) is effective in reducing depression, anxiety, and stress (54), that mindfulness-based cognitive therapy is effective in improving psychological symptoms and health-related quality of life (55), and that peer-led self-management education is effective in improving physical health-related quality of life (56). Meta-analytic data have shown cognitive behavioral therapy to be effective in reducing psychological symptoms, such as depression, in rheumatoid arthritis (57). Mindfulness-based interventions (primary mindfulness-based stress reduction and mindfulness-based cognitive therapy) have also been shown to reduce depression in this patient population in meta-analysis (58).

RECOMMENDATIONS FOR FUTURE RESEARCH AND CLINICAL CARE

In a recent position paper, mental health experts advocated for research priorities for the COVID-19 pandemic (59). Suggested priorities are grouped according to individual and population levels. At an individual level, the authors suggest investigating the risk of COVID-19 on mental health outcomes, including anxiety, depression, and suicide, and determining how to optimize mentally healthy lifestyles after COVID-19 and associated social and physical distancing. At a population level, they promote 1) researching the mental health consequences of social isolation on vulnerable groups, 2) examining the effect of traditional and social media consumption related to COVID-19 on mental health, and 3) examining optimal methods for promoting adherence to COVID-19–related restrictions while maintaining mental health. The goal of this research is to develop evidence-based interventions and strategies aimed at optimizing mental health at a population and individual level. When discussing vulnerable groups, the authors specifically mention those with pre-existing physical health issues, which means that patients with autoimmune diseases should be considered a priority group when it comes to COVID-19–related mental health research, according to this framework.

When setting research priorities regarding the effect of COVID-19 on patients with autoimmune disorders, mental health issues should be included. The first step in future studies would be to characterize the effect of COVID-19 on mental health in persons with autoimmune disease. This may involve questionnaires aimed at evaluating general distress, quality of life, depression, anxiety, and post-traumatic stress. One research group based in British Columbia, Canada, is conducting such an online study (Understanding the Experiences of Individuals With Rheumatic Diseases During the COVID-19 Pandemic [UNIFIED-rheum]) assessing the effect of the pandemic on individuals with rheumatic diseases (https://www.unifiedcovid.com/rheumatic-disease-survey). This study includes specific questions regarding the effect of the pandemic on mental health and will provide valuable information for further research and interventions.

Potential contributors to emotional distress, as described above, include feelings of discrimination related to societal response to COVID-19, fear of infection and uncertainty related to medical treatment (particularly immunosuppressive treatment), diminished access to usual care and resources, previous health care experiences, and the exacerbating effect of social isolation. These may be explored further, for instance, with observational and qualitative research methods, which can elicit additional themes. Resiliency and effective coping strategies should also be included in research to explore factors that may be helpful in developing interventions.

Once the scope and quality of psychological distress in persons with autoimmune disease has been determined (or in concert with this work), research and clinical programming should focus on interventions. For persons with autoimmune disease, effective mental health interventions may be similar to those suggested for the general population described above. Mental health treatments such as cognitive behavioral therapy and mindfulness-based interventions have evidence for patients with autoimmune disease but must be studied in virtual form and may benefit from being tailored to address factors that are specific to COVID-19. Further research should examine the efficacy of multicomponent interventions aimed at optimizing care for persons with autoimmune disease and including factors aimed at improving mental health and reducing distress. Such studies should include mental health–related outcome measures with validity evidence for different autoimmune diseases (5).

Table 2 summarizes potential clinical interventions and research foci tailored for persons with autoimmune disease and aimed at addressing issues described in this review, as follows: identifying mental health challenges, addressing emotions related to society's response to COVID-19, gaps in usual care and uncertainty, increasing social support, and making use of existing coping strategies. These interventions are intended for use in settings such as primary care and autoimmune disease specialty clinics. However, although they are based on the related literature cited above, these interventions are not evidence-based for use during the COVID-19 pandemic, hence, our inclusion of potential research foci and methodology to study these items.

In conclusion, individuals with autoimmune disease may be uniquely vulnerable to mental health challenges during the COVID-19 pandemic because of COVID-19–specific, autoimmune

Table 2. Framework of potential mental health interventions and research foci for persons with autoimmune disease during COVID-19

Concept	Potential Clinical Intervention	Potential Research Focus and Methodology
Identifying mental health challenges in patients with autoimmune disease during the pandemic and referring to appropriate resources	Screening for common mental health challenges during routine clinical encounters. Consider using screening instruments with validity evidence for autoimmune diseases (5) Referral to mental health resources when indicated	Part of multicomponent intervention studies examining provision of clinical care to patients with autoimmune disease during COVID-19 and its aftermath Controlled intervention trials examining provision of evidence-based mental health care virtually, potentially with components addressing COVID-19–specific factors (eg, uncertainty and isolation)
Exploring emotions related to societal response to COVID-19	Openly inquiring as to the effect that societal response to COVID-19 has had on patients with autoimmune disease Validating feelings of discrimination and devaluation and offering emotional support.	Observational/qualitative studies exploring the mental health impact of COVID-19 on persons with autoimmune disease and the contributing factors
Addressing gaps in usual care and resources	Ensuring that patients are able to maintain connection with their usual care providers, and that they know how to access help for any urgent issues. May be facilitated by electronic resources, such as telemedicine and clinic websites Using virtual care or telephone to involve patients' usual support system in appointments when indicated Investigating the psychological impact of virtual care for serious illness, particularly for those who are newly diagnosed	Quality improvement or health services research investigating optimal service delivery during the pandemic Observational/qualitative studies investigating the effect of virtual care on the illness experience
Addressing disease-related uncertainty	Providing accurate and disease-specific information, including realistic information about fatality rates, updates regarding medication availability, and guidance about safety of immunosuppressant and related medications during the pandemic (suggest referring to the American College of Rheumatology guidance document for up-to-date and evidence-based information: https://www.rheumatology.org/Portals/0/Files/ACR-COVID-19-Clinical-Guidance-Summary-Patients-with-Rheumatic-Diseases.pdf). Providing education about public health guidance and infection control strategies. Keeping relevant information up to date and communicating information quickly to patients using reliable sources, for instance via the websites of patient groups or of autoimmune disease clinics (refer to https://www.aarda.org/aarda-covid-19/ for a compendium of patient-centered resources)	Part of multicomponent intervention studies examining provision of clinical care to patients with autoimmune disease during COVID-19 and its aftermath
Exploring impact of previous health care experience	Discussing how previous health experiences may contribute to patients' current feelings about the pandemic in both positive and negative ways	Observational/qualitative studies exploring the risk factors for heightened distress during COVID-19
Exploring impact of social isolation and promoting social connection	Assessing the impact of physical distancing on persons with autoimmune disease and their families/support systems Encouraging maintaining regular social connections via virtual means or in person within public health guidelines when appropriate Encouraging interested patients to connect with online peer-support communities	Observational/qualitative studies exploring the impact that COVID-19 restrictions have had on the mental health and social relationships of persons with autoimmune disease Controlled intervention studies investigating the benefit of virtual peer support communities
Building on resilience	Reflecting on coping skills that patients have developed in response to adversity and how they may be able to make use of these during the pandemic	Observational/qualitative studies exploring how persons with autoimmune disease have coped with COVID-19–related stress

COVID-19, coronavirus disease 2019.

disease–specific, and societal factors. Research and clinical interventions should take into account all of these variables. The pandemic and its aftermath are likely to be a long road, and the mental health of persons with autoimmune disease must be addressed during this process in order to provide high-quality person-centered care.

AUTHOR CONTRIBUTIONS

Study conception and design. Bingham, Rozenbojm, Chong-East, Touma.

Acquisition of data. Bingham.

Analysis and interpretation of data. Bingham.

REFERENCES

1. Wang C, Pan R, Wan X, Tan Y, Xu L, Ho CS, et al. Immediate psychological responses and associated factors during the initial stage of the 2019 coronavirus disease (COVID-19) epidemic among the general population in China. Int J Environ Res Public Health 2020;17:1729.

2. Barlow JH, Macey SJ, Struthers GR. Gender, depression, and ankylosing spondylitis. Arthritis Care Res 1993;6:45–51.

3. Eldeiry D, Zandy M, Tayer-Shifman OE, Kwan A, Marzouk S, Su J, et al. Association between depression and anxiety with skin and musculoskeletal clinical phenotypes in systemic lupus erythematosus. Rheumatology (Oxford) 2020;59:3211–20.

4. Jeppesen R, Benros ME. Autoimmune diseases and psychotic disorders. Front Psychiatry 2019;10:131.

5. Kwan A, Katz P, Touma Z. The assessment of anxiety and depression and its associated factors in SLE. Curr Rheumatol Rev 2019;15:90–8.

6. Mccormick N, Trupin L, Yelin EH, Katz PP. Socioeconomic predictors of incident depression in systemic lupus erythematosus. Arthritis Care Res (Hoboken) 2018;70:104–13.

7. Pryce CR, Fontana A. Depression in autoimmune diseases. Curr Top Behav Neurosci 2017;31:139–54.

8. Vallerand IA, Patten SB, Barnabe C. Depression and the risk of rheumatoid arthritis. Curr Opin Rheumatol 2019;31:279–84.

9. Mikuls TR, Johnson SR, Fraenkel L, Arasaratnam RJ, Baden LR, Bermas BL, et al. American College of Rheumatology guidance for the management of adult patients with rheumatic disease during the COVID-19 pandemic: version 1. Arthritis Rheumatol 2020. E-pub ahead of print.

10. Pfefferbaum B, North CS. Mental health and the covid-19 pandemic. N Engl J Med 2020;383:510–2.

11. Ferrari R. Writing narrative style literature reviews. Medical Writing 2015;24:230–5.

12. Hartmann-Boyce J, Mahtani KR. Supporting people with long-term conditions (LTCs) during national emergencies. Centre for Evidence-Based Medicine. March 2020. URL: https://www.cebm.net/covid-19/supporting-people-with-long-term-conditions-ltcs-during-national-emergencies/.

13. Wankowicz P, Szylinska A, Rotter I. Evaluation of mental health factors among people with systemic lupus erythematosus during the SARS-CoV-2 pandemic. J Clin Med 2020;9:2872.

14. Ziadé N, el Kibbi L, Hmamouchi I, Abdulateef N, Halabi H, Hamdi W, et al. Impact of the COVID-19 pandemic on patients with chronic rheumatic diseases: a study in 15 Arab countries. Int J Rheum Dis. 2020. E-pub ahead of print.

15. Elran-Barak R, Mozeikov M. One month into the reinforcement of social distancing due to the COVID-19 Outbreak: subjective health, health behaviors, and loneliness among people with chronic medical conditions. Int J Environ Res Public Health 2020;17:5403.

16. Louvardi M, Pelekasis P, Chrousos GP, Darviri C. Mental health in chronic disease patients during the COVID-19 quarantine in Greece. Palliat Support Care 2020;18:394–9.

17. Seyahi E, Poyraz BC, Sut N, Akdogan S, Hamuryudan V. The psychological state and changes in the routine of the patients with rheumatic diseases during the coronavirus disease (COVID-19) outbreak in Turkey: a web-based cross-sectional survey. Rheumatol Int 2020;40:1229–38.

18. Friedman U. We were warned. The Atlantic. March 2020. URL: https://www.theatlantic.com/politics/archive/2020/03/pandemic-coronavirus-united-states-trump-cdc/608215/.

19. Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19). Centers for Disease Control and Prevention. 2020. URL: https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-higher-risk.html.

20. World Health Organization. Q&A on coronaviruses (COVID-19). 2020. URL: https://www.who.int/news-room/q-a-detail/q-a-coronaviruses.

21. Mastroianni J. 'Real people won't die': rhetoric around who is at risk of coronavirus infection sparks debate over ageism, ableism. National Post. March 2020. URL: https://nationalpost.com/news/world/real-people-wont-die-why-the-rhetoric-around-who-is-at-risk-for-coronavirus-is-so-harmful.

22. Kessler RC, Mickelson KD, Williams DR. The prevalence, distribution, and mental health correlates of perceived discrimination in the United States. J Health Soc Behav 1999;40:208–30.

23. Perrin PC, McCabe OL, Everly GS, Links JM. Preparing for an influenza pandemic: mental health considerations. Prehosp Disaster Med 2009;24:223–30.

24. Lebel S, Mutsaers B, Tomei C, Leclair CS, Jones G, Petricone-Westwood D, et al. Health anxiety and illness-related fears across diverse chronic illnesses: a systematic review on conceptualization, measurement, prevalence, course, and correlates. PLoS One 2020;15:e0234124.

25. Figueroa-Parra G, Aguirre-Garcia GM, Gamboa-Alonso CM, Camacho-Ortiz A, Galarza-Delgado DA. Are my patients with rheumatic diseases at higher risk of COVID-19? [Letter] Ann Rheum Dis 2020;79:839–40.

26. Johnson LM, Zautra AJ, Davis MC. The role of illness uncertainty on coping with fibromyalgia symptoms. Health Psychol 2006;25:696–703.

27. Bresge A. People with compromised immune systems are living in fear of COVID-19. CTV News. March 2020. URL: https://www.ctvnews.ca/health/coronavirus/people-with-compromised-immune-systems-are-living-in-fear-of-covid-19-1.4857255.

28. Wallis A. What it's like to be immunocompromised during the COVID-19 outbreak. Healthline. March 2020. URL: https://www.healthline.com/health-news/what-its-like-to-be-immunocompromised-during-the-covid-19-outbreak.

29. Peschken CA. Possible consequences of a shortage of hydroxychloroquine for patients with systemic lupus erythematosus amid the COVID-19 pandemic. J Rheumatol 2020;47:787–90.

30. Yao X, Ye F, Zhang M, Cui C, Huang B, Niu P, et al. In vitro antiviral activity and projection of optimized dosing design of hydroxychloroquine for the treatment of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Clin Infect Dis 2020;71:732–9.

31. Gautret P, Lagier J-C, Parola P, Hoang VT, Meddeb L, Mailhe M, et al. Hydroxychloroquine and azithromycin as a treatment of COVID-19: results of an open-label non-randomized clinical trial. Int J Antimicrob Agents 2020;56:105949.

32. Yazdany J, Kim AHJ. Use of hydroxychloroquine and chloroquine during the COVID-19 pandemic: what every clinician should know. Ann Intern Med 2020;172:754–5.

33. Jakhar D, Kaur I. Potential of chloroquine and hydroxychloroquine to treat COVID-19 causes fears of shortages among people with systemic lupus erythematosus. Nat Med 2020;26:632.

34. Mahevas M, Tran V-T, Roumier M, Chabrol A, Paule R, Guillaud C, et al. Clinical efficacy of hydroxychloroquine in patients with covid-19 pneumonia who require oxygen: observational comparative study using routine care data. BMJ 2020;369:m1844.

35. Tang W, Cao Z, Han M, Wang Z, Chen J, Sun W, et al. Hydroxychloroquine in patients with mainly mild to moderate coronavirus

disease 2019: open label, randomised controlled trial. BMJ 2020; 369:m1849.

36. Food and Drug Administration. Coronavirus (COVID-19) update: FDA revokes emergency use authorization for chloroquine and hydroxychloroquine. June 2020. URL: https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-revokes-emergency-use-authorization-chloroquine-and.

37. Ahmed T, Lodhi SH, Kapadia S, Shah GV. Community and health-care system-related factors feeding the phenomenon of evading medical attention for time-dependent emergencies during COVID-19 crisis. BMJ Case Rep 2020;13:e237817.

38. Back AL, Curtis JR. Evidence-based case reviews: communicating bad news. West J Med 2002;176:177–80.

39. Butow PN, Kazemi JN, Beeney LJ, Griffin AM, Dunn SM, Tattersall MH. When the diagnosis is cancer: patient communication experiences and preferences. Cancer 1996;77:2630–7.

40. Bumb M, Keefe J, Miller L, Overcash J. Breaking bad news: an evidence-based review of communication models for oncology nurses. Clin J Oncol Nurs 2017;21:573–80.

41. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 2000;5:302–11.

42. Barskova T, Oesterreich R. Post-traumatic growth in people living with a serious medical condition and its relations to physical and mental health: a systematic review. Disabil Rehabil 2009;31:1709–33.

43. Sukantarat K, Greer S, Brett S, Williamson R. Physical and psychological sequelae of critical illness. Br J Health Psychol 2007;12:65–74.

44. Leano A, Korman MB, Goldberg L, Ellis J. Are we missing PTSD in our patients with cancer? Part I. Can Oncol Nurs J 2019;29:141–6.

45. Alonzo AA. The experience of chronic illness and post-traumatic stress disorder: the consequences of cumulative adversity. Soc Sci Med 2000;50:1475–84.

46. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 2020;395:912–20.

47. Dawson DL, Golijani-Moghaddam N. COVID-19: psychological flexibility, coping, mental health, and wellbeing in the UK during the pandemic. J Contextual Behav Sci 2020;17:126–34.

48. Joglekar S, Sastry N, Coulson NS, Taylor SJ, Patel A, Duschinsky R, et al. How online communities of people with long-term conditions function and evolve: network analysis of the structure and dynamics of the Asthma UK and British Lung Foundation Online Communities. J Med Internet Res 2018;20:e238.

49. Kingod N, Cleal B, Wahlberg A, Husted GR. Online peer-to-peer communities in the daily lives of people with chronic illness: a qualitative systematic review. Qual Health Res 2017;27:89–99.

50. Hefferon K, Grealy M, Mutrie N. Post-traumatic growth and life threatening physical illness: a systematic review of the qualitative literature. Br J Health Psychol 2009;14:343–78.

51. Thombs BD, Kwakkenbos L, Carrier M-E, Bourgeault A, Tao L, Harb S, et al. Protocol for a partially nested randomised controlled trial to evaluate the effectiveness of the scleroderma patient-centered intervention network COVID-19 home-isolation activities together (SPIN-CHAT) program to reduce anxiety among at-risk scleroderma patients. J Psychosom Res 2020;135:110132.

52. Chinese University of Hong Kong, sponsor. Use of telemedicine for follow-up of systemic lupus erythematosus ("TeleSLE") in the COVID-19 outbreak: a pragmatic randomised controlled trial. ClinicalTrials.gov identifier: NCT04368299; 2020.

53. Bauerle A, Skoda E-M, Dörrie N, Böttcher J, Teufel M. Psychological support in times of COVID-19: the Essen community-based CoPE concept. J Public Health (Oxf) 2020;42:649–50.

54. Navarrete-Navarrete N, Peralta-Ramírez MI, Sabio-Sánchez JM, Coín MA, Robles-Ortega H, Hidalgo-Tenorio C, et al. Efficacy of cognitive behavioural therapy for the treatment of chronic stress in patients with lupus erythematosus: a randomized controlled trial. Psychother Psychosom 2010;79:107–15.

55. Solati K, Mousavi M, Kheiri S, Hasanpour-Dehkordi A. The effectiveness of mindfulness-based cognitive therapy on psychological symptoms and quality of life in systemic lupus erythematosus patients: a randomized controlled trial. Oman Med J 2017;32:378–85.

56. Drenkard C, Dunlop-Thomas C, Easley K, Bao G, Brady T, Lim SS. Benefits of a self-management program in low-income African-American women with systemic lupus erythematosus: results of a pilot test. Lupus 2012;21:1586–93.

57. Astin JA, Beckner W, Soeken K, Hochberg MC, Berman B. Psychological interventions for rheumatoid arthritis: a meta-analysis of randomized controlled trials. Arthritis Rheum 2002;47:291–302.

58. Zhou B, Wang G, Hong Y, Xu S, Wang J, Yu H, et al. Mindfulness interventions for rheumatoid arthritis: a systematic review and meta-analysis. Complement Ther Clin Pract 2020;39:101088.

59. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. Lancet Psychiatry 2020;7:547–60.