



THE JOURNEYS OF PATIENTS WITH AUTOIMMUNE DISEASES DURING THE COVID-19 PANDEMIC

**Angela S. Abines,
Erin Gray Ader,
Kia M. Almirol,
Liana G. Arcita,
Corine M. Balan,
Angelica F. Bengil,
Kyla Mae V. Bernancio,
Julla Hermierose R. Bustamante,
Sofia Ysabel B. Cervantes,
Angela Rose Dimen,
Vivian Catherine C. Camanoⁱ**

College of Nursing,
Adamson University,
Philippines

Abstract:

This study explored the lived experiences of individuals with autoimmune diseases during the COVID-19 pandemic, uncovering their emotional struggles, challenges, coping mechanisms, and the broader implications of their condition amidst a global health crisis. Using a qualitative research approach, data were gathered through in-depth interviews with five participants from the Philippines, aged 20-70, and analyzed using Colaizzi's method. Four central themes emerged: Emotional Struggles, Challenges, Adaptability, and Coping Mechanisms. Participants revealed that stress, anxiety, and fear were pervasive emotional stressors that exacerbated their autoimmune conditions. These struggles were compounded by challenges such as physical limitations, adherence to strict routines, and dietary restrictions, all intensified by the pandemic's restrictions and protocols. Despite these difficulties, participants demonstrated adaptability through changes in habits, adherence to medical regimens, and positive mindsets. Coping mechanisms were largely influenced by support systems, including family, friends, and healthcare providers, which played a crucial role in fostering resilience. The findings highlight the interplay between psychological, physical, and social dimensions in managing autoimmune diseases, particularly during a global health emergency. Recommendations include integrating mental health support into standard care, promoting telemedicine, fostering community support, and leveraging technology to

ⁱ Correspondence: vivian.catherine.camano@adamson.edu.ph

enhance patient care. The study emphasizes the importance of holistic interventions and public health policies that address both the medical and emotional needs of individuals with autoimmune diseases. Future research should investigate the long-term impacts of the pandemic on this population to inform more comprehensive and sustainable healthcare strategies.

Keywords: autoimmune diseases, COVID-19 pandemic, emotional resilience, coping mechanisms, holistic healthcare

1. Introduction

The COVID-19 pandemic profoundly impacted immunocompromised individuals, especially those with autoimmune diseases. Autoimmune disorders, characterized by the immune system attacking healthy tissues, require lifelong management, and the pandemic magnified the health risks and emotional stress faced by these patients. This study explores the lived experiences of Filipino autoimmune patients during the pandemic, focusing on their struggles and coping mechanisms.

Autoimmune diseases are diverse and complex, with over 80 identified types, most lacking a definitive cure (National Institute of Environmental Health Sciences, 2022). The pandemic's novelty and the emergence of SARS-CoV-2 variants intensified challenges for these patients, highlighting the need for qualitative research in resource-limited settings like the Philippines, where local studies remain sparse. This research addresses two questions:

- 1) What were the struggles of autoimmune patients during the COVID-19 pandemic?
- 2) How did they cope with these struggles?

The study's findings are relevant to health organizations, government agencies, nursing students, and future researchers. Health organizations can use the data to improve interventions, while policymakers can develop better assistance programs. Nursing students can gain insights into the challenges faced by autoimmune patients, and future researchers can build on these findings.

Data were collected through online interviews with five Filipino participants aged 20 to 70, including both COVID-19 -positive and -negative individuals. Four key themes emerged: Emotional Struggles, Challenges, Adaptability, and Coping Mechanisms. While the study's small sample size and remote data collection methods limited generalizability, it provides valuable insights into the pandemic's impact on this vulnerable population and informs future healthcare strategies.

2. Literature Review

Since December 2019, the COVID-19 pandemic has posed significant challenges to public health, particularly for patients with autoimmune diseases. According to Graunge *et al.*

(2020), there is no evidence of a greater incidence of COVID-19 in patients with autoimmune rheumatic diseases, though once infected, they face a small but significantly increased risk of mortality. Similarly, Matheny *et al.* (2021) highlighted concerns that immunosuppressive treatments and illness characteristics in autoimmune patients elevate their risk of infection and complications. Pro-inflammatory cytokine storms are associated with worse outcomes, such as hospitalization, critical care needs, and death. Public health authorities worldwide have recommended stringent prevention measures, including shielding, isolation, hand hygiene, and social distancing, to protect this vulnerable group due to the lack of vaccines and therapeutic options during the early stages of the pandemic.

Wang *et al.* (2022) evaluated COVID-19 risk in individuals with rheumatic diseases, noting the profound and lasting societal impact of the pandemic. Their meta-analysis revealed that the incidence of COVID-19 among patients with rheumatic diseases was 89%, with hospitalization, ICU admission, mechanical ventilation, and fatality rates reaching 91%. Regional variations in these outcomes were statistically significant, underscoring the heightened vulnerability of these patients.

The pandemic's impact extended to the mental health of patients with autoimmune diseases. Research by Bingham *et al.* (2020) revealed increased psychological distress among this population, driven by fear of infection, uncertainty regarding immunosuppressive treatments, diminished access to care, and the isolating effects of societal responses to COVID-19. Cognitive therapy and peer-led self-management education were identified as effective interventions for improving psychological symptoms and quality of life in these patients.

The interplay between chronic inflammatory and autoimmune diseases during COVID-19 has been complex. SARS-CoV-2 infection triggers a spectrum of immune responses, ranging from regulated antiviral activity to dysfunctional autoimmune reactions, including cytokine release syndrome and systemic hyperinflammation. These dysregulated immune responses have been implicated in severe disease progression and multi-organ damage.

A systematic review utilizing the Medline database from PubMed identified articles published in English between January 1 and September 20, 2020. Peer-reviewed studies, including case reports and series, were included, with LN and FM independently reviewing articles to ensure they met inclusion criteria. Discussions resolved any uncertainties, providing a robust synthesis of relevant findings.

Liu *et al.* (2020) investigated the relationship between SARS-CoV-2 infection and autoimmunity, noting that lymphopenia is associated with severe illness and may predict symptom severity and mortality. Neutrophilia, linked to excessive neutrophil extracellular traps, contributes to lung injury in severe COVID-19 cases. Additionally, 45% of patients tested positive for autoantibodies, correlating with worse prognoses. Coagulopathy emerged as a potentially fatal complication of SARS-CoV-2 infection.

Research from Italy demonstrated that autoimmune patients had a similar SARS-CoV-2 infection rate as the general population. However, these patients' struggles were amplified during the pandemic due to the chronic nature of their conditions. Hamdani (2021) highlighted the unique challenges faced by autoimmune patients, including managing symptoms and accessing care amidst pandemic disruptions.

Tan *et al.* (2021) compared outcomes between autoimmune patients infected with COVID-19 and those with seasonal influenza. Their study of over 133,000 patients revealed that autoimmune patients hospitalized with COVID-19 were predominantly female and aged 50 and above. Hypertension, chronic kidney disease, and heart disease were prevalent comorbidities. COVID-19 patients experienced worsened respiratory complications, such as pneumonia and acute respiratory distress syndrome, compared to influenza patients.

Ansarin *et al.* (2022) examined factors associated with COVID-19 hospitalization among autoimmune patients. Severe outcomes, including ICU admission and death, were linked to immunomodulatory treatments and disease-related immune dysfunction. In Canada, Mukherjee's study found that autoantibodies persisted in 30% of long-term COVID-19 patients, suggesting a link between post-COVID symptoms and autoimmune conditions. Blood samples from patients treated in Vancouver and Hamilton hospitals revealed prolonged autoantibody presence, indicating a need for specialist evaluation for potential autoimmune illnesses.

3. Materials and Methods

The research methods employed in this study include the research locale, sampling technique, data gathering procedure, and data analysis. The study involved Filipino participants selected from various locations in the Philippines. The research setting was feasible due to the researchers' ability to access participants through online platforms such as Zoom and Google Meet. Five participants diagnosed with autoimmune diseases were interviewed about their experiences during the COVID-19 pandemic.

The researchers employed a nonprobability purposive sampling technique, also referred to as judgment sampling. This approach allowed the researchers to use their expertise to select a sample that best addressed the study's objectives. Purposive sampling is particularly suited to qualitative research, where the aim is to gather in-depth insights into a specific phenomenon rather than generalize findings to a larger population. Five participants aged 20 to 70 years were selected based on the following criteria: diagnosis with an autoimmune disease and availability for online interviews. Among them, three participants had not contracted COVID-19, while two had. The purposeful selection of these individuals ensured a diverse range of perspectives on living with autoimmune diseases during the pandemic.

Before conducting data collection, the researchers obtained approval for the research instrument and informed consent from participants. Participants were initially

contacted through a formal letter of invitation, outlining the study's general and specific objectives. Written consent was secured before the interviews commenced. The interviews, conducted through Zoom or Google Meet, focused on understanding the daily lives and experiences of patients with autoimmune diseases during the pandemic. After the interviews, the researchers expressed gratitude to the participants for their time and contributions.

The Colaizzi method was employed for data analysis, a widely used approach in phenomenological research to explore lived experiences and interpret subjective accounts. This systematic process involved several steps. First, the researchers read and reread all transcribed interviews to gain a comprehensive understanding of participants' experiences. Key phrases and statements directly related to the phenomenon were identified and extracted, and these extracted statements were categorized into broader meanings to represent the essence of participants' experiences. Related meanings were grouped into themes, which were then organized into thematic clusters. An exhaustive description was compiled, synthesizing the thematic clusters into a cohesive narrative. The exhaustive description was condensed to highlight the fundamental structure of the phenomenon. Finally, findings were reviewed and discussed with experts and independent reviewers to ensure alignment with participants' accounts.

This thorough approach enabled the researchers to uncover essential themes and structures from the participants' descriptions. Themes such as emotional struggles, adaptability, and coping mechanisms emerged, providing a detailed understanding of the phenomenon under investigation.

4. Results and Discussion

Participants were recruited randomly around the Philippines, specifically participants who were diagnosed with autoimmune diseases. There were five participants—four females and one male. Three of the participants are registered nurses, one is a student, and one is a dialysis patient.

The researchers used the Colaizzi method to analyze data. The researchers formulated theme clusters evidently related to the transcribed statements of the participants. The statements were clustered into four theme clusters.

Cluster Theme 1: Emotional Struggles

The study revealed that stress, anxiety, and fear significantly exacerbated the conditions of participants with autoimmune diseases. These emotional struggles were common among the majority of the participants, who cited various stressors that intensified their symptoms and impacted their well-being. Emotional stress emerged as a central factor in the worsening of autoimmune conditions, highlighting the critical need for psychological resilience and emotional support for this vulnerable group.

- **Stress, Anxiety, and Fear**

Participants reported that the pandemic heightened their emotional stress, which in turn aggravated their health conditions. For instance, one participant shared how the vaccine rollout and constant visits to the hospital created a stressful environment: *"It was stressful, especially during the vaccine rollout. I was always in the hospital, and I kept seeing people in the ER, with so many outside, especially during the first year when there wasn't a vaccine yet."* (Leni)

Another participant emphasized the connection between stress and autoimmune triggers, stating that psoriasis is activated by excessive stress: *"Psoriasis gets triggered when you're overly stressed. So, a stress-free environment is really important. When you get stressed, overthink, or lose sleep excessively, one after the other, it also triggers the condition."* (Mary)

The added responsibilities of working from home while managing an illness, as highlighted by a participant with Graves' Disease, further compounded the stress: *"It's an added factor that, even though I had COVID, I was still working from home, which added to the stress. I understand my condition, which is Graves' Disease, and the more stressed I get, the more active the illness becomes."* (Issa)

Hyperthyroidism's connection to stress was also highlighted by another participant, who noted the unique challenges of managing the condition as a woman in her 30s to 40s: *"In your 30s to 40s, it's common for hyperthyroidism to develop. It's also common in females, and what shocked me the most is how big of a factor stress is. I realized that the pandemic became really stressful for me."* (Phoebe)

Participants also expressed feelings of anxiety and fear, particularly about the unpredictability of the situation and their heightened risk of infection due to their compromised immune systems. One participant remarked: *"There's anxiousness because the situation is so unpredictable, and we are at high risk of getting infected. That's really our concern... I've had an autoimmune condition for a long time."* (Leni)

Another participant shared the dual burden of worrying for their family's safety while managing their own health: *"Actually, first of all, I have a family. So initially, I felt threatened for their welfare because they might get infected. And I also understand that there might be untoward reactions for me as well. Because the more I'm exposed to infection, the higher the possibility that my thyroid becomes more active. So naturally, I also experienced anxiety. It wasn't full-blown anxiety yet, just a little bit of worry. No, I was really worried because there might be an untoward reaction for me."* (Issa)

The emotional toll also manifested physically, as described by a participant who rarely experienced illness before the pandemic: *"When it comes to emotions, I was also affected. Because I feel... I'm not the type of person who gets sick. During that time, I felt weak."* (Phoebe)

Interestingly, one participant appeared less affected emotionally, finding solace in the support of friends: *"I wasn't really sad or scared because my friends were always there for me. We even worked out together since there was no school."*

In summary, emotional struggles were a critical theme that emerged from the narratives. Stress, anxiety, and fear created a feedback loop that not only intensified the

participants' physical symptoms but also highlighted the importance of emotional resilience, support systems, and stress management in coping with autoimmune diseases during the pandemic.

Cluster Theme 2: Challenges

The study highlighted the various challenges faced by participants with autoimmune diseases during the pandemic, particularly the limitations imposed on their environments, routines, habits, and diets to prevent the worsening of their conditions. These challenges required significant lifestyle adjustments, often exacerbating the participants' physical and emotional burdens.

- **Limitations**

Participants had to restrict their exposure to certain triggers, such as sunlight, crowded places, and unhealthy foods, which could aggravate their symptoms. For example, one participant shared: *"I'm not allowed in sunlight. So for outings like that, especially during summer, there's only a specific time I can go out. And if it's unavoidable, I can only stay for a short while because it can trigger joint pain and cause rashes. That's why I avoid sun exposure. Also, I'm not allowed to stay up late. There are also dietary restrictions because of my dialysis, especially when it comes to water."* (Leni)

Another participant highlighted the precautions taken to avoid crowded places and maintain safer outdoor activities: *"I avoid crowded places now. And during summer, my family really loves swimming, but we now avoid swimming pools and only look for beaches instead. It's just like that. We avoid places with a lot of people, and pools where the water isn't replaced, unlike beaches with natural water. That's just how it is."* (Mary)

Rest became a vital component for recovery, especially for participants managing illnesses triggered by stress. As one participant noted: *"...and try to rest, you know. That's also one of my issues because when I'm given work, I keep going even if I'm sick. But the doctor told me to try resting because, as I mentioned, stress really triggers my thyroid. So, I reduced my online work while recovering from COVID. That's all I can say. Of course, it was hard because I had so much backlog."* (Issa)

Other participants shared their commitment to healthier habits to manage their conditions: *"Apart from medications, I stuck to a diet. I reduced fast foods and unhealthy meals. I cut back on those."* (Phoebe)

Another participant discussed adjusting their diet to manage symptoms: *"The signs and symptoms make me feel dizzy quickly. And when I eat sweets, I start shaking right away. So, I reduced those. I can't manage them anymore. Not particularly sweets, but I don't eat much now because I get scolded, and the fridge is locked."* (Leody)

- **Facing the COVID-19 Pandemic**

The pandemic's restrictions and protocols also posed challenges for participants. For some, staying at home and adhering to safety measures became routine. As one

participant described: *“Since I wasn’t allowed to go out, I just stayed at home, watched TV, and did regular activities. My husband was also out of work then, so I had company at home.”* (Leni)

Others highlighted how protocols impacted their conditions. For instance, one participant shared how increased hygiene practices exacerbated psoriasis: *“As I’ve said before, we used to bathe once a day, but now it’s more frequent. Since after work, whether tired or not, I always take a bath. Sometimes, I notice that the extra baths dry out my psoriasis, so I’ve been buying more moisturizing creams. Since the pandemic, I’ve been bathing more often, and using alcohol also dries out my skin.”* (Mary)

In summary, the challenges faced by participants during the pandemic underscored the need for tailored interventions and support. From managing physical limitations to adapting to pandemic protocols, participants demonstrated resilience and resourcefulness in navigating their health conditions amid unprecedented circumstances.

Cluster Theme 3: Adaptability

The study highlighted the adaptability of participants with autoimmune diseases in managing their health during the pandemic. Despite the struggles, participants demonstrated resilience by adjusting their routines, adhering to treatment regimens, and maintaining a positive mindset to mitigate the impact of their conditions.

- **Adapting to Environmental Changes**

Participants employed various strategies to adapt to changes in their environment and lifestyle, allowing them to manage their symptoms and maintain daily functionality. One participant noted the heightened precautions they took: *“Since I’m easily susceptible to infections, I had to triple my efforts in being cautious. There were so many additional considerations I had to make.”* (Leni)

For some, maintaining a sense of normalcy became essential, as one participant shared: *“Actually, it’s just normal. It’s like everyone’s life. I wake up, prepare breakfast for my husband and me, then work. That’s it.”* (Mary)

Others focused on balancing work and rest to prevent triggering symptoms. A participant managing thyroid issues explained: *“It’s work, but one task at a time. I tried my best to rest so that I wouldn’t overstimulate or trigger my thyroid condition.”* (Issa)

A positive mindset also played a critical role, as highlighted by one participant: *“Medication takes years to work. You can’t just stop because if you do, stress might cause a spike again. Control is crucial. I also read up on my condition and decided to focus on being positive. If I let myself feel down or sad, nothing will happen. I wouldn’t improve. So that’s it.”* (Phoebe)

- **Adherence to Treatment Regimens**

Participants emphasized the importance of consistently following their treatment regimens to manage their conditions effectively. This included taking prescribed medications, attending regular checkups, and combining treatments with healthy habits.

One participant highlighted their use of topical steroids: *“I only apply topical steroids when there are a lot of sores. If it’s mild, I avoid it since steroids aren’t ideal for us.”* (Mary)

Another shared their strict adherence to medical advice during a COVID-19 infection: *“When I got COVID, I just followed the doctor’s orders. Drink lots of water, take prescribed medications like Fluimucil, and so on. I’m very particular about following up with my doctor because I have Graves’ Disease.”* (Issa)

Long-term medication adherence was also crucial for managing symptoms, as one participant explained: *“Strict adherence to treatment regimens is essential. I’ve been taking maintenance medications for years, and I do my best not to miss a dose. Medications take years to work, and stopping could cause complications.”* (Phoebe)

However, challenges remained for some, as one participant admitted to maintaining medication but skipping regular checkups: *“I’m taking maintenance medications like metformin and insulin injections, but I don’t visit the doctor regularly for checkups.”* (Leody)

Participants also combined medications with other health management strategies, such as diet adjustments and regular follow-ups. As one participant noted: *“I’ve reduced fast foods and unhealthy meals, stuck to my diet, and maintained a positive mindset. Strict adherence to treatment regimens is crucial for improvement.”* (Phoebe)

In conclusion, the adaptability of participants demonstrated their resilience in managing autoimmune diseases during the pandemic. Through environmental adjustments, adherence to treatments, and a positive outlook, participants navigated the challenges of their conditions with resourcefulness and determination.

Cluster Theme 4: Coping Mechanism

The study highlighted various coping mechanisms adopted by participants with autoimmune diseases to manage their symptoms and maintain functionality during the pandemic. These mechanisms were pivotal in mitigating the emotional and physical burdens posed by their conditions.

- **Support System**

The presence of supportive family members and friends emerged as a significant coping mechanism. Four participants expressed how their loved ones played a vital role in uplifting their spirits and providing practical assistance. One participant shared: *“My husband stayed at home with me, but most of my relatives were far away, so they couldn’t accompany me during dialysis sessions. However, they would regularly check on me, and in terms of financial support for my dialysis, I could rely on them.”* (Leni)

Another participant highlighted how her husband and relatives helped ease her situation: *“My husband stayed home and left food for me. Some of my other relatives, who live nearby, would drop off food and fruits. We would do video calls and chat every day.”* (Mary)

One participant expressed that her motivation to recover stemmed from her children and her husband, who is also a nurse: *“My children are my motivation to get better.”*

I would think about how I could care for them if I were sick. My husband, who is also a nurse, was my biggest support. He knows what to say to me and what I need to do.” (Phoebe)

Friendships also provided emotional strength, as another participant noted: *“I wasn’t sad or scared because my friends were there for me. We even worked out together since we were bored and there was no school.” (Leody)*

- **Learning Outcomes**

The pandemic experience brought about various learning outcomes for participants, shaping how they approached their health and challenges. One participant reflected on how stress from working at home while having COVID-19 affected her health: *“Even though I had COVID, I kept working from home, which added to the stress. I know that with Graves’ Disease, the more stressed I am, the worse it gets.” (Issa)*

Another participant recounted how following her doctor’s orders helped during her recovery: *“When I had COVID, I followed the doctor’s advice, like drinking lots of water and taking medications like Fluimucil. I just followed their orders.” (Leni)*

Some participants emphasized the importance of seeking medical attention and managing responsibilities. One shared: *“Before I started taking medications, I struggled to balance my responsibilities at home and the symptoms I was experiencing. Eventually, I sought medical attention because, as strong women, we try to handle things on our own before asking for help. But I realized that managing my condition requires help from others.” (Phoebe)*

Another participant highlighted how diet adjustments improved her condition: *“My aunt scolded me because my previous diet plan wasn’t working. After I was diagnosed, I improved. Now, I understand my own diet and what triggers my symptoms, unlike before when I was just guessing.” (Leody)*

In conclusion, the coping mechanisms and learning outcomes shared by the participants underscore the importance of strong support systems, adherence to medical advice, and personal resilience in managing autoimmune diseases during challenging times. These strategies enabled them to navigate the difficulties posed by their conditions while maintaining hope and functionality.

5. Recommendations

Healthcare providers should implement comprehensive stress management and mental health support programs tailored to individuals with autoimmune diseases, incorporating regular mental health assessments and counseling services into standard care.

Public health authorities must develop policies ensuring the availability of remote healthcare services, such as telemedicine, to provide continuous care for patients with chronic illnesses while raising public awareness about autoimmune diseases and their unique challenges during health crises.

Educational institutions should integrate knowledge about autoimmune diseases into the curriculum for medical and allied health students to enhance the understanding and empathy of future healthcare professionals.

Community-based support groups for individuals with autoimmune diseases should be established to facilitate peer learning and emotional support, while families and friends are encouraged to actively support patients' health and emotional well-being. Future research should focus on the long-term impacts of the pandemic on individuals with autoimmune diseases, particularly the psychological, social, and physical dimensions, while investigating the effectiveness of different coping strategies and interventions.

Government agencies should allocate funding for programs that enhance the quality of life for individuals with autoimmune diseases, including subsidies for medications, dietary support, and financial assistance for healthcare services.

Finally, technological advancements should be leveraged to create tools and applications that assist patients in monitoring their symptoms, managing stress, and adhering to treatment regimens, ensuring these tools are accessible and user-friendly for diverse populations.

6. Conclusion

This study highlighted the multifaceted challenges and coping strategies of individuals with autoimmune diseases during the COVID-19 pandemic. Emotional struggles, physical limitations, and the necessity for adaptive coping mechanisms emerged as key themes that defined their experiences. Despite these challenges, participants demonstrated resilience, supported by strong social systems and a commitment to managing their health.

The findings of this study underscore the importance of holistic health interventions that address both the physical and emotional needs of individuals with autoimmune diseases. Healthcare providers must prioritize stress management programs and mental health support, as these factors significantly influence the progression of autoimmune conditions. Additionally, the study highlights the need for accessible healthcare services and continuous patient education to empower individuals in managing their conditions effectively.

From a public health perspective, policies that support the provision of remote healthcare services, including telemedicine, are crucial. The pandemic has amplified the necessity for such innovations, ensuring that patients with chronic illnesses receive uninterrupted care.

Future research should explore the long-term impacts of the pandemic on individuals with autoimmune diseases, focusing on the interplay between psychological resilience, disease progression, and healthcare delivery. The insights gained from this

study provide a foundation for developing patient-centered interventions and fostering resilience among individuals facing similar challenges in the future.

Conflict of Interest Statement

The authors of this study declare that there is no conflict of interest regarding the publication of this research. No financial, personal, or professional relationships have influenced the research process, data collection, analysis, or interpretation of the findings. This work has been conducted with integrity and transparency, adhering to ethical guidelines to ensure unbiased and independent results.

About the Author(s)

The authors are nursing students guided by their faculty adviser who worked together to complete this research as part of their academic journey.

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