

# **ARTICLE**



# Living with spinal cord injury during COVID-19: a qualitative study of impacts of the pandemic in Nepal

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STUDY DESIGN: A qualitative study using focus group discussion.

**OBJECTIVE:** To explore the impacts of COVID-19 on multiple aspects of the lives of individuals living with spinal cord injury (SCI) in Nepal.

SETTING: Community settings in Nepal.

**METHODS:** A qualitative phenomenological study was conducted using two virtual focus group discussions. Fourteen individuals with SCI residing in different parts of Nepal participated. A thematic analysis approach was used to analyze and interpret the participants' responses.

**RESULTS:** The four key themes for the impacts of COVID-19 on individuals with SCI were: (1) physical health with subthemes of (a) difficulty due to the presence of COVID-19 symptoms and (b) deterioration in secondary conditions; (2) mental health with subthemes of (c) constant fear of COVID-19 and (d) psychological distress; (3) social life with subthemes of (e) social stigma and (f) social isolation, and (4) economic problems with subthemes of (g) financial burden and (i) inadequate resources.

**CONCLUSIONS:** The pandemic has tremendously impacted the physical, mental, social, and economic aspects of the lives of individuals with SCI. These, in turn, could impede the functioning and well-being of this population. The utilization of telehealth to provide education, psychosocial support, social awareness programs, and the provision of essential medical supplies appear necessary to maintain and improve the well-being of individuals with SCI during this pandemic. Future studies using an in-depth interview approach and psychosocial interventions are recommended.

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# INTRODUCTION

The exponential growth and spread of the COVID-19 pandemic in the world have resulted in tremendous impacts on everyone's life. COVID-19 has drastically altered individuals' lives globally, influencing multiple aspects of society, including daily living, academic life, employment, social interactions, activities, and health care services [1-4]. The uncertainty associated with the virus (e.g., its fatality, transmissibility, severity, and duration), economic burdens, and social distancing have increased mental health issues among many populations [5-9]. For example, a large-scale study conducted in China at the start of the outbreak reported that among 56,679 participants, 27.9% had depression, 31.6% anxiety, and 29.2% insomnia [3]. A systematic review of studies conducted in eight countries found a high rate of psychological issues such as stress, anxiety, depression, and post-traumatic stress disorder among the general population. Sociodemographic characteristics such as gender, age, employment status, and health condition make someone more likely to experience COVID-19-related health issues than others [9].

The impacts of pandemics are likely to be more severe for certain groups of people who are vulnerable due to their pre-existing physical, psychological, and social status. The COVID-19 pandemic has magnified and complicated existing barriers that

people with disabilities (PWDs) face [6, 10]. PWDs, including those with spinal cord injuries (SCI), experience persistent challenges due to their limited ability to perform daily activities [11, 12]. People with SCI are at greater risk of contracting the virus because they tend to have pre-existing conditions, comorbidities, and barriers to implementing safety measures (e.g., personal hygiene) and accessing public information and health care resources. Moreover, it is almost impossible for them to maintain social distancing as many must rely entirely or partially on caregivers for daily living activities [13]. In turn, these dependencies place them at a greater risk of developing physical and psychosocial complications, jeopardizing their health and well-being. Even though this population is more vulnerable than the general population, studies that address issues or challenges that people with SCI face due to these dual stressful events (i.e., COVID-19 and SCI) are limited [6, 14].

Some SCI-related clinical factors (e.g., fever, fatigue, and respiratory infection) possibly delay the accurate diagnosis of COVID-19 in people with SCI. Furthermore, secondary conditions associated with SCI are likely to increase morbidity and mortality due to COVID-19 [2, 14]. Since the beginning of COVID-19, many studies have investigated the effects of the pandemic in a range of populations, including adults without disabilities, students, health

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care professionals, and veterans [3, 5, 7–9, 15, 16]. However, limited research exists on how the pandemic has impacted PWDs, including those with SCI. The studies conducted in the general population have used quantitative design, limiting their insight into individuals' perspectives within their context. A qualitative approach facilitates a better insight into the perceived impacts of the pandemic [6]. A qualitative study conducted in the United Kingdom identified loss of access to health services, health anxiety, and social isolation as crucial challenges due to COVID-19 among people with SCI [6]. More studies are needed to understand the impacts or challenges of COVID-19 on top of SCI-related difficulties.

As of November 29, 2021, there were 821,121 confirmed cases of COVID-19 and 11,524 deaths in Nepal [17]. The second wave of COVID-19, which started in July 2021 as the contagious Delta variant, forced millions of Nepalese to stay inside their home due to a lockdown, resulting in the lack of food and other essential resources. Nepal is a developing country with limited health resources, and most people with SCI reside in rural areas [18]. This results in negative impacts because of the lack of healthcare resources and medical supplies needed to manage activities of daily living. People with SCI need regular health care and medical supplies, including pain medications, products to manage neurogenic bladder and bowel, wounds, and assistive devices. In addition, many people with SCI use clean intermittent catheterization (CIC) daily to drain their urine [19]. With the increased

COVID-19 cases due to the Delta variant, Nepal's government frequently implemented nationwide lockdown policies, limiting access to healthcare resources, social activities, and transportation. The lockdown and restriction also disrupted outpatients and routine health care services in many parts of the country [8].

This study aimed to identify the negative impacts of COVID-19 on the lives of individuals living with SCI in Nepal. The qualitative approach helps to gain better insights into the problems of individuals with SCI from their perspectives. The findings may guide the development of adequate support, care, and interventions, including tailored psychoeducation for individuals with SCI.

#### **METHODS**

A qualitative phenomenological study using focus group discussion (FGD) was conducted. The study was approved by the Institutional Review Board of the Nepal Health Research Council (Reg. No. 251/2021P). The researchers reached out to the president of Spinal Cord Injury Network Nepal (SCINN), one of the SCI organizations in Nepal. The participants were recruited using the convenience sampling technique with the help of the president of SCINN. The following criteria were used to select participants: (a) SCI; (b) age 18 years or older; and (c) comprehension of the Nepali language. Their caregivers helped participants who had complete tetraplegia and could not use a mobile phone or laptop. Participants from different parts of Nepal (e.g., Kathmandu, Dhangadi, Itahari, Kailai, Kaski, and Kavre) were included in the study to recruit a representative sample.

**Table 1.** Themes, subthemes, and examples of participants quotations.

Quotations	Subthemes	Themes
"I had pneumonia, difficulty in breathing, eating, and sleeping. These symptoms on top of my disability made it difficult to perform my daily living activities" (43 years, male).  "I had a UTI, and I got Foley's catheter inserted, but there was still leaking from the catheter. I could not go to the hospital, and it was really annoying" (34 years, male).  "I was having a menstruation problem for five months, but because of the lockdown, I could not go to the hospital for many days" (31 years, female).	Difficulty due to COVID-19 symptoms Deterioration in secondary conditions	Physical health impacts
"I am missing home. I want to go home and live with my family, but I am afraid I may transmit COVID-19 to my father who has a heart problem. Therefore, I am staying here in my apartment feeling lonely and hopeless" (30 years, female). "I had depressive feelings, and I felt my life is worthless because I thought I have negatively impacted the lives of many people around me" (57 years, male).	Constant fear of COVID-19 Psychological distress	Mental health impacts
"I had returned from Japan and had to stay in quarantine for 14 days. First, people's attitude toward people with disabilities is obviously different. On top of this, society's attitude is negative toward people who return from foreign countries during this pandemic. Even though I was tested negative for COVID-19, people did not trust me, and nobody wanted to meet with me" (29 years, female). "My family and I felt a lot of social pressure. I suffered from the virus. People with whom I was in contact were asking me to get their COVID tested. It was expensive to test COVID at that time. They blamed me that I had met them so that I might have transmitted the virus to all of them. Therefore, they believed it was my responsibility to arrange the testing for them" (41 years, male). "Because I cannot go outside, I cannot talk with and share my feelings with others. I have to spend most of my time alone in my apartment. I used to go home during festivals, but I could not even go during festivals to meet my family and relatives last year. That was so tough for me, and I even do not know if I can visit family during festivals this year" (31 years, female).	Social stigma Social isolation	Social impacts
"The treatment cost of COVID-19 is extremely expensive. I was admitted to the isolation unit, which was very expensive. We, people with SCI, are financially weak because of unemployment, and we must rely on family for financial support. That said, the treatment cost for COVID-19 is not affordable for us. Having COVID-19 increases our financial burden as well" (57 years, male).  "I live alone, and I have a caregiver who comes from outside every day. However, during this pandemic, my house owner asked me not to invite anyone inside the home. Therefore, I have difficulty performing activities of daily living because of the absence of my caregiver" (37 years, female).  "Most of the housing is not accessible for us. We have to share bathrooms and many other common places with many tenants, and isolation at rented apartments is not feasible" (33 years, male).	Financial burden Inadequate resources (e.g., medical supplies, caregivers, buildings).	Economic problem

**Table 2.** Demographic and injury-related characteristics of the participants (N = 14).

Demographics variables		%
Gender identity		
Male	7	50.0
Female	7	50.0
Marital status		
Single	4	28.6
Married	8	57.1
Windowed/Divorced	2	14.3
Education		
Illiterate	1	7.1
Secondary level	2	14.3
High school	4	28.6
Bachelor's degree	3	21.4
Master's degree	4	28.6
Employment		
Employed	9	64.3
Unemployed	5	35.7
Level of injury		
Cervical	2	14.3
Thoracic	3	21.4
Lumber	9	64.3
Completeness of injury		
Complete	12	85.7
Incomplete	2	14.3
Cause of injury		
Motor vehicle accident	5	35.7
Fall	8	57.1
Spinal tumor	1	7.1
Time since injury		
1–5 years	1	7.1
6–10 years	6	42.9
11–15 years	3	21.4
16–20 years	4	28.6

The FGDs were conducted in June and July 2021. Fourteen participants were recruited, and through Zoom, two FGDs were run with seven participants in each. The virtual FGD was a safe and convenient way to reach out to people with SCI living in different places in Nepal. A recent study also supports the viability of Zoom for qualitative data collection [20]. The two FGD sessions were guided by the following open-ended question: "how has COVID-19 impacted your life?" All three researchers facilitated and co-facilitated the FGDs using Zoom in interviews lasting almost two hours. The participants were allowed time and leeway to discuss their issues related to the impacts of COVID-19. The facilitators utilized follow-up questions and probes to encourage participants to express the effects of the pandemic in multiple domains of their lives. The recorded discussion was transcribed verbatim and analyzed, and the themes, subthemes, and guotes were translated from Nepali to English. The researchers further interviewed two participants individually to check the validity and completeness of the information collected during the FGDs. Member checking was performed with one participant to ensure the credibility of the results. Each participant received Nepalese Rupee (NPR) 300 as an incentive for participating in the study.

The data were analyzed and interpreted using thematic analysis as guided by Braun and Clarke [21]. Thematic analysis is one of the best approaches for interpreting qualitative data to find patterns of meaning across the responses of many participants [21]. All authors were involved in the analysis. After closely reading the interview transcripts, the first author created initial codes and subthemes in NVivo. Similar codes and relevant

descriptions were clustered together. Upon the three researchers agreeing on subthemes, the second author checked all transcripts to determine whether all materials were coded for each subtheme. The second and the third authors assisted the first author in clustering the subthemes to generate the themes. All authors discussed their thoughts, ideas, and interpretations to identify themes that best capture the participants' shared experiences and thoroughly reviewed the themes and their corresponding quotes. The results section and Table 1 provide details on the themes, subthemes, and associated quotations.

#### **Participants**

The average age of the participants was 38 years (SD=9), ranging from 24 to 57 years. Equal numbers of females and males participated in the study. Of the 14 participants, six had contracted COVID-19 and recovered by the time they participated in the study. Table 2 presents other demographic and injury-related information of the participants.

#### **RESULTS**

The study participants noted a range of COVID-19-related challenges. Four key themes emerged, representing perceived negative impacts of COVID-19 in multiple aspects of their lives: (a) physical health impacts, (b) mental health impacts, (c) social impacts, and (d) economic problems. Two sub-themes were identified for each theme. The themes, subthemes, and some participants' quotations are provided below.

### Physical health impacts

One significant adverse impact of COVID-19 was on participants' physical health. Difficulty due to COVID-19 symptoms and further deterioration in secondary conditions emerged as two subthemes. As of the interview date, six participants had contracted COVID-19 and experienced COVID-19-related symptoms. Four of them had been hospitalized for many days for the treatment of COVID-19. Beyond existing SCI-related complications, COVID-19 symptoms, including respiratory problems, fever, body pain, anorexia, insomnia, and fatigue, severely impacted their life. One participant recalled a time when he was hospitalized due to COVID-19:

I experienced almost all the symptoms of COVID-19, like breathing difficulty, insomnia for several nights, loss of appetite, fever, and severe body pain. I still feel shortness of breath and fatigue when attempting to do even mild physical activities like walking or lifting. (43 years, male)

For many participants, regardless of whether they contracted COVID-19 or not, the pandemic *negatively affected SCI-related secondary conditions*. The lockdowns and the inability to receive healthcare services and rehabilitation resulted in or worsened secondary conditions such as urinary tract infection (UTI), pressure ulcer, and pain. For example, one participant stated, "many of us experienced retention of urine due to the lack of CIC and lidocaine jelly; many could not go to the hospital to treat a pressure ulcer and pain" (51 years, male).

# Mental health impacts

All participants reported that the pandemic has adversely impacted their mental health from a mild to a severe degree. Two sub-themes emerged: constant fear of COVID-19 and psychological distress. The participants *felt constant fear of contracting COVID-19* or transmitting it to other people around them. They also expressed concerns that contracting COVID-19 would more severely impact their health than that of the general population. One participant stated:

There is always a fear of contracting COVID-19 from family members or caregivers who often go outside. That makes me worried all the time. I often fear that if we, the individuals with

SCI, would get COVID-19, how would we be able to face it or overcome it. It will be tough for us. (43 years, male)

Along with fear, one major impact of COVID-19 was *psychological distress* among the participants. Many participants noted experiencing non-specific symptoms of stress, anxiety, and depression due to the pandemic. A participant who was hospitalized due to COVID-19 shared:

The impact of COVID-19 is so huge that I thought I no longer wanted to stay alive because many people showed a negative attitude towards me as if I had committed a crime. I felt a burden to my family. I felt reluctant to visit my relatives, and I could not meet and interact with people, which was extremely frustrating and stressful. (57 years, male)

#### **Social impacts**

Social stigma or discrimination due to the negative societal attitudes toward COVID-19 and social isolation were two significant social challenges that many participants with SCI experienced. Regarding *social stigma*, participants, particularly those who contracted COVID-19, reported lacking emotional support from their neighbors and relatives. A few of them also expressed perceived discrimination by their immediate family members. For example, one participant who was hospitalized for the treatment of COVID-19 described the attitudes of his neighbors as follows:

After I got discharged from the hospital and returned home, all the people renting rooms in my house did not come home for many days because they were scared that I would transmit the virus. My friends, relatives, and neighbors did not come to see me, and I felt they were avoiding me. No one came to see how I was doing; it did hurt me so badly. Such discriminatory attitudes of people made me think that I contaminated or destroyed the entire town. (57 years, male)

Many participants felt that social distancing and the lockdown that resulted in *social isolation* further intensified their psychological distress. One of them shared, "In the first phase of COVID-19, social distancing, inability to meet with family and friends made my life more difficult. It was notably challenging when we had to stay in isolation and quarantine" (51 years, male). It was even more difficult for those who contracted the virus. A 30-year-old female who lives independently stated:

After being discharged from the hospital, I had trouble reaching out to people to ask for help. Because I live alone, I had a hard time grocery shopping, and I also did not feel comfortable asking others for help. I had no one to help me with my activities of daily living. I felt lonely; I felt stressed, thinking that I might not meet my family again. Of course, no one wants to come closer to us who have COVID-19. (30 years, female)

## **Economic problems**

Economic problems with sub-themes of the financial burden and inadequate resources were identified as another major impact of COVID-19. Participants reported experiencing *financial burdens* due to the lockdown and inflated medical and healthcare supplies costs. One participant residing in rural Nepal noted:

My business is closed, and there is no alternative source of income for my family. I do not have enough supplies and [not] enough money to pay the extra cost of supplies, including catheters, gloves, jelly, sanitizers, et cetera. The cost of medical

supplies is highly inflated due to COVID-19. I am having difficulty buying even Dettol and catheters. (44 years, male)

Many participants reported the *inadequate resources*, including medical supplies, the unavailability of caregivers, and architectural or physical barriers (e.g., inaccessible hospital buildings). Overwhelmingly, the participants shared the lack of supplies due to the pandemic. Especially many participants living in rural areas or outside of the capital city had difficulty accessing medications and health care supplies that they needed for their symptom management and self-care. One participant stated:

We [i.e., person with SCI] need medicines and medical supplies like xylocaine jelly, catheters, diapers, gloves, antiseptic solutions, and other daily items. The main problem for us during this pandemic is a lack of these resources. We did not have stock of these items. For example, we usually use a clean intermittent catheter for a week, and now we have to use it for almost two months. Many individuals with SCI are experiencing a lack of health care supplies for daily use, and some cannot even afford to buy a packet of gloves. Even disposable gloves have to be washed with Dettol and reused. (37 years, male)

#### Follow-up individual interview and member checking

One female and one male participant who were further interviewed one-on-one to validate the findings from FGDs expressed the same problems revealed in the FGDs. The female described the impacts of COVID-19 on mental health as, "I saw a woman of my age suddenly dying in the spinal injury rehabilitation center because of COVID-19. My oxygen saturation was normal, but I still felt breathlessness and palpitations due to the fear of dying. I was hopeless for many days" (31 years, female). Regarding inadequate resources, the male participant added, "I had to stay in the hospital for four days. The restroom was not wheelchair friendly, and I had to defecate in a bedpan in the bed. This suffering was way more difficult than what I experienced when I got SCI from the accident" (43 years, male).

The results were returned to one participant for member checking, who confirmed the accuracy and resonance of results with his experience.

# **DISCUSSION**

This qualitative study strengthened our understanding of the negative impacts of COVID-19 on people with SCI living in different parts of Nepal. COVID-19's direct effect on health, the lockdown and restrictions placed on people as preventive measures, disruption in health care services, and fear associated with the pandemic negatively affected the physical and mental health and social and financial aspects of the lives of people with SCI. Almost half of the participants were infected with the virus. In line with the findings from previous studies [10, 22], the participants experienced many COVID-19-related symptoms and also reported long-term impacts, such as fatigue and shortness of breath while performing physical activities. Individuals with SCI are more vulnerable to developing respiratory complications, and the direct effect of COVID-19 on respiratory functioning may lead to poor health outcomes [23].

The pandemic has contributed to the deterioration of secondary conditions that individuals with SCI often experience. The lockdown and restrictions have affected delivery and utilization of health care services and resources in Nepal. Most outpatient' services were closed [8]. The lack of resources has further jeopardized the lives of people with SCI. Many individuals could not seek health care services to manage their secondary conditions. Because some of the symptoms of COVID-19 and SCI-related secondary conditions are overlapping, it has been

challenging to screen this vulnerable population and triage accordingly during this pandemic [2, 23].

Furthermore, the present study results revealed that individuals with SCI experience constant fear and psychological distress due to increased COVID-19 cases, lockdowns, and other social restrictions. Because of their immunocompromised status and the necessity of utilizing caregivers, individuals with SCI feel more vulnerable to contracting the virus and not recovering from it. Consistent with the literature [1, 6], fear of getting infected with the virus and transmitting the infection to others were the prominent causes of psychological distress. Even though the pandemic has resulted in mental health issues in various populations [1, 4, 6–8, 15], individuals with SCI may experience more challenges due to the dual effects of the pandemic and injury-related functional limitations and secondary conditions.

The participants were also concerned about the discriminatory attitude of society and the unavailability of social support during the pandemic. The pandemic substantially increased the fear of morbidity and mortality among the general population; that is why those with the COVID-19 infection were usually stigmatized and isolated [24]. Many participants, specifically those who contracted the virus, experienced negative social attitudes and social isolation. Social support is consistently associated with higher resilience and well-being in people with SCI [18, 25]. The lack of adequate support due to people's negative attitudes and social isolation may increase distress among this group. Social isolation and distancing are effective preventive measures for COVID-19 [8]; however, these measures have disrupted the social lives of many individuals, regardless of whether they have a disability. The inability to participate in social activities, connect with friends and family, and engage in meaningful work has amplified psychological distress in people with SCI [6].

Financial burden and inadequate resources are considerable challenges for individuals with SCI. Consistent with previous findings that indicated a COVID-related financial burden among the adult population [1], the participants in this study expressed stress resulting from the loss of income and the inflated cost of medical supplies and health care services. The participants who contracted COVID-19 were more likely to face financial crises due to the high costs of hospitalization and treatment than those who did not contract the infection. These findings mirror the issues expressed by people with SCI living in the United Kingdom [6]. Hearn and colleagues noted the lack of access to health services and SCI-specific support as the most common concern among this population. However, unlike the participants in the Hearn and colleagues report, participants in the current study reported a financial burden and the inability to afford basic medical supplies. The economic impacts of COVID-19 are enormous in countries with limited resources compared to developed countries [1, 26]. People with SCI consistently require medical supplies, including medications, to manage secondary conditions. The inadequacy or inaccessibility of such services and supplies can result in negative health consequences, further affecting their daily activities [6]. Even though hospital facilities provide treatment to patients with COVID-19, the isolation and quarantine services provided by the government and hospitals are not sufficient and, importantly, less accessible to people with SCI. This concern has further increased their fear of contracting COVID-19.

Considering the transmissibility of COVID-19, the need for social distancing, and geographical features of Nepal (e.g., hills, mountains), telehealth with proper education for individuals with SCI and their caregivers, could minimize physical and psychological problems. Telehealth is effective in circumventing the trouble and risk of visiting the hospital during this inconvenient time [23, 27]. Literature suggests that positive psychological interventions such as best possible self exercise, positive affirmations, gratitude exercise, yoga, and mindfulness meditation potentially minimize negative emotions and improve mental

health and well-being [26]. Mindfulness-based interventions could help individuals accept the challenges associated with the pandemic, deal with change and loss, and channel their distress toward positive growth and resilience [28]. Rehabilitation practitioners can utilize these interventions using telehealth to mitigate the effects of COVID-19 in people with SCI.

To reduce the stigma associated with COVID-19, stakeholders, including ministries of health, SCI organizations, health institutions, community leaders, and social workers, can bring awareness to the public by developing and implementing anti-stigma interventions focusing on reducing negative and depreciative terminology related to the pandemic, discouraging stigmatizing behavior towards those who have contracted the virus, and identifying the myth and misunderstanding related to the transmissibility of COVID-19 [29].

Because lack of resources is a crucial challenge for people with SCI living in developing countries [1, 26], provision of relief packages, including essential medications (e.g., pain medicine), basic SCI-related supplies (e.g., catheters, uro-bags, gloves, and cleaning equipment), and food, during the crisis could relieve some financial burdens. Similarly, development and implementation of architectural or physical accessibility policies for individuals with SCI is imperative in isolation centers and health institutions. Therefore, ministries of health, SCI institutions, and health facilities must develop the basic policies and protocols, and programs at the national level, addressing health care access for PWDs, including those with SCI.

The current study has several implications; however, it is essential to acknowledge its limitations. The virtual FGD was convenient and effective; nonetheless, the participants might not feel comfortable sharing all their information in the virtual session compared to an in-person session. In addition, FGD might sometimes limit the opportunity to explore the detailed information from each participant. Two participants were further interviewed individually to address this issue. A further study using a large sample size and a one-on-one interview approach is recommended to thoroughly investigate the experiences of people with SCI and replicate the current study. Many participants in the present study were socially active, employed, and living in urban areas. Further study is needed to better capture the unique problems that disadvantaged and underserved people with SCI living in rural areas experience.

## CONCLUSION

This qualitative study explored the COVID-19-related challenges faced by individuals living with SCI in Nepal. The impacts of COVID-19 on people with SCI are enormous, especially on those who contracted the virus. Helping these people satisfy their physical and psychosocial needs is very important. Notably, a dearth of resources in developing countries seems to be a significant concern, further intensifying the pandemic's adverse effects among people with SCI. Therefore, adequate health care supplies, mental health services, and awareness seem imperative. Intervention studies are recommended to address the physical, psychosocial, and financial issues and improve well-being in this population.

## **DATA AVAILABILITY**

Data are available from the corresponding author on reasonable request.

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## **AUTHOR CONTRIBUTIONS**

All authors were responsible for designing the study, collecting data, extracting and analyzing data, interpreting results, and writing the manuscript.

#### **COMPETING INTERESTS**

The authors declare no competing interests.

# **ADDITIONAL INFORMATION**

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