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Spinal cord injury and COVID-19: Information, prevention and challenges

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***Abstract*---**Objective: To analyze access to information, adopted prevention measures, opinions on isolation, and the feelings and difficulties of people with spinal cord injury (SCI) during the COVID-19. Study design and methods: This is a quantitative, cross-sectional, descriptive and analytical study. Sample of 211 participants, between 18 and 67 years, of which 140 were male. Results: Among the participants, 87.7% stated they had received information about the pandemic; 90.1% were in favor of social isolation; and 59.0% referred to having both positive and negative feelings. Conclusion: Individuals with SCI in Brazil have faced significant challenges during the COVID-19 pandemic.

***Keywords*---**2019-nCoV, viral infection, spinal cord injuries, disease prevention.

Introduction

The start of 2020 was marked by a serious pandemic triggered by the novel coronavirus (SARS-CoV-2), which causes the disease known as COVID-19. It is characterized by respiratory symptoms that can range from influenza-like symptoms to severe acute respiratory syndrome (SARS) and is associated with significant infection and mortality rates.[1] The virus spreads quickly. It is transmitted through respiratory droplets or nasal secretions of the infected person and can survive for long periods in the environment, on objects and surfaces.[2]

To date, no effective drugs to prevent or cure the disease have been identified; however, never have so many studies been produced in such a short time. Studies and clinical trials are being conducted worldwide in the search for knowledge on COVID-19. [3,4] The World Health Organization strongly recommends prevention measures to slow contamination by the novel coronavirus until new results are obtained.[3,4]

For this purpose, the World Health Organization has established a priority that helps health workers and governments ensure people with disabilities, such as spinal cord injury (SCI), have access to health services in emergencies. However,

the challenges faced during the pandemic forced the development of new recommendations specifically for vulnerable groups such as people with disabilities.[5]

Individuals with SCI experience altered physiology and may exhibit different symptoms in response to viral infections, with a greater risk of underlying respiratory comorbidities, which may increase the lethality of COVID-19 in this population.[2,6-9] The response to infectious agents in a person with SCI, such as fever and cough, is altered, making it difficult to diagnose COVID-19 and increasing the need for support and more intensive care in the early stages of infection. Consequently, besides the possibility of patients being exposed to other pathogens and complications, more strain is put on health systems, when the ideal strategy would be prevention measures, such as social isolation.[6,8]

Social isolation for people with SCI is an issue that involves challenges. In many cases, the caregivers must remain socially isolated with the patients, resulting in extra costs.[9] Moreover, people in rehabilitation who use respiratory ventilation and care equipment are also affected by isolation as a result of changes in the care routines of elective specialized health centers and rely solely on emergency services. This interferes with their rehabilitation, causes complications related to their physical disabilities and affects the mental health of these individuals and that of their family members.[6,9]

The pandemic in Brazil initially emerged in more upscale neighborhoods among people of high socioeconomic level and, subsequently, spread to the poorest populations of the capital cities and regions of the country. Sociocultural differences can affect the way we fight the pandemic. Hygiene stands out as a difficulty for people with SCI in poorer populations during the pandemic, possibly associated with the shortage of drinking water commonly observed in countries such as India and Brazil.[10,11] In short, the provision of personalized socioeconomic solutions to the problem is an important stage in rehabilitation during the pandemic.

With the increased risk of intercurrences for people with SCI, public policies such as training health workers to provide care to this population based on their individual needs, human resources in health systems, minimizing the risk of infections, including COVID-19, and the identification and early diagnosis of symptoms, preventing other infections, are measures that enable rapid hospital discharge and the return of people with SCI to their communities.[2,12] Therefore, until clinical studies and care protocols are well established, reliable information and respect for the guidelines of health organizations are the best way to confront the current situation.

Nevertheless, Brazilian studies focused on people with disabilities remain scarce, especially those on the reality of people with SCI. The context in which these people live, including their special health requirements, should be considered together with their legitimate challenges and concerns when creating public policies to fight the COVID-19 pandemic. Thus, the present study aims to investigate and analyze access to information, adopted prevention measures,

opinions on isolation, and the feelings and difficulties of people with spinal cord injury during the COVID-19 pandemic in Brazil.

Study Design and Methods

This is a quantitative, cross-sectional, descriptive and analytical study. As research was based on data collected from the Internet, the scope was all of Brazil. The study was approved by the Ethics and Research Committee (CEP) of the University of São Paulo, according to Resolution 466/12, of the National Research Ethics Council of the Ministry of Health, which addresses ethics in research with human beings, CAAE protocol No. 07355319.9.0000.5393, for all participants. The online questionnaire was only completed after the participants accepted the informed consent statement.

The study participants were Brazilian adults with SCI and internet access from the volunteer register for participation in research on Spinal Cord Injury of the Neurorehab research group. Participants who did not complete the questionnaire were excluded. Data were collected via the Survey Monkey® online platform using a questionnaire created and previously validated by a group of nurses with experience in the rehabilitation of people with SCI. The online questionnaire consisted of 20 multiple choice and three open-ended questions, available at (https://pt.surveymonkey.com/r/forpapers), sent via messaging (WhatsApp) and e-mail to around 1,300 volunteers registered on the Neurorehab Research Nucleus database. Data were collected between May and June 2020, from a total of 211 participants.

The data collected on SurveyMonkey® were transferred directly to the Statistical Package of Social Science software, version 22.0 and R version 3.3.0. Regarding education, the variable was categorized according to complete or incomplete level of education. The data were subjected to descriptive analysis by means of absolute frequencies, mean, median, percentage, standard deviation, minimum and maximum. The means were followed by the standard deviation and the median of the interquartile range. The Pearson Chi-squared test was used to analyze the association between categorical variables. A significance level of 0.05 was considered.

Results

The sample consisted of 211 participants, of whom 140 (66.3%) were male and 71 (33.6%) were female. The age ranged from 18 to 67 years, with a mean of 41.4 years old (SD=10.13) at the time of research. According to the participants, 65.4% had paraplegia, 32.7% had tetraplegia and 1.9% were unable to respond. Table 1 shows the distribution of participants according to sociodemographic data of marital status, education and family income. (Table 1)

Table 1 – Distribution of participants according to sociodemographic data, (n=211), Brazil, 2023

Origin	Frequency	Percent %
North	8	3.8
Central-West	15	7.1
Northeast	24	11.4
South	37	17.5
Southeast	127	60.2
Education	Frequency	Percent %
Complete or incomplete higher education	89	42.2
Complete or incomplete secondary education	55	26.0
Graduate studies	46	21.8
Complete or incomplete primary education	20	9.5
No schooling	1	0.5
Family income	Frequency	Percent %
Up to 2 MW*	44	20.8
Up to 1 MW*	40	19.0
Up to 3 MW*	37	17.5
More than 3 to 5 MW*	36	17.1
More than 6 to 10 MW*	33	15.7
More than 10 MW*	13	6.1
Don't know/Rather not say	8	3.8
Occupation	Frequency	Percent %
Retired	105	49.8
Employed or self-employed	54	25.6
Unemployed	22	10.4
Student	19	9.0
Medical leave	11	5.2
TOTAL	211	100.0

*MW = Brazil's minimum wage in 2020, reference value: BRL 1,045.00
Source: Author

As observed in Table 1, most participants had complete or incomplete higher education and earned a family income of up to three minimum wages. It was also found that 65.4% of the 211 participants were not working or studying and only 34.6% were employed or self-employed or studying. Moreover, 55.0% of the participants depended exclusively on social welfare income from the government.
Regarding marital status, the majority reported being single (47.9%), followed by married (35.5%), divorced (14.2%) and widowed (2.4%). When asked about having a caregiver to help with their daily activities, 59.7% of the participants reported having a caregiver and 40.3% reported that they did not have help. Participants with paraplegia had less need for caregivers (48.6%) than those with tetraplegia (84.1%), ($p \leq 0.001$, Pearson Chi-squared test).

Figure 1 shows the distribution of participants according to access to information on coronavirus/COVID-19. (Figure1)

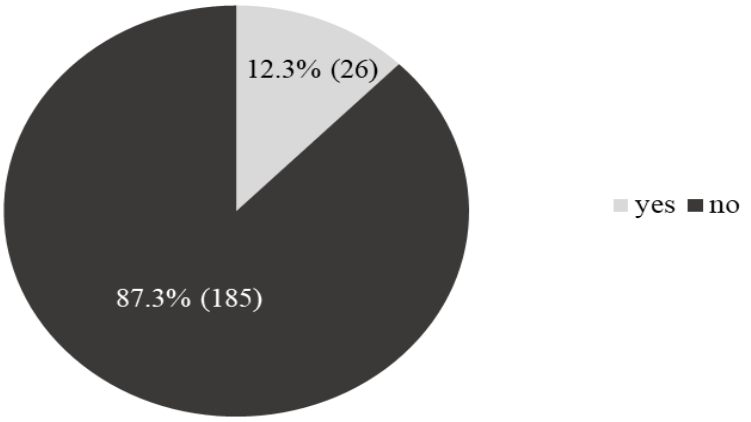

Figure 1 - Distribution of participants according to access to information on COVID-19 (n=211). Brazil, 2023

The 185 participants who reported they had received some information on coronavirus/COVID-19 were also asked about the way in which they had received this information, as shown in figure 2 (more than one option was provided). (Figure 2)

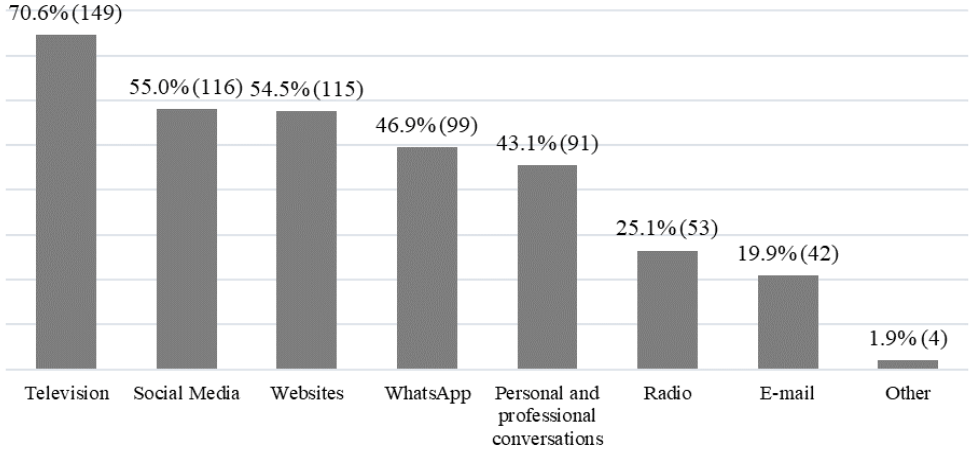

Figure 2 - Distribution of participants who received information on COVID-19, according to the media used (n=186). Brazil, 2023

Most of the participants received their information from the television, followed by social media, web pages/sites and messaging applications. In the category Other, respondents reported that information was obtained from scientific articles. Figure 3 shows the opinion of participants on social isolation, conceptualized as the need to stay at home, not going out into the streets unnecessarily, and maintaining physical distance from other people. (Figure 3)

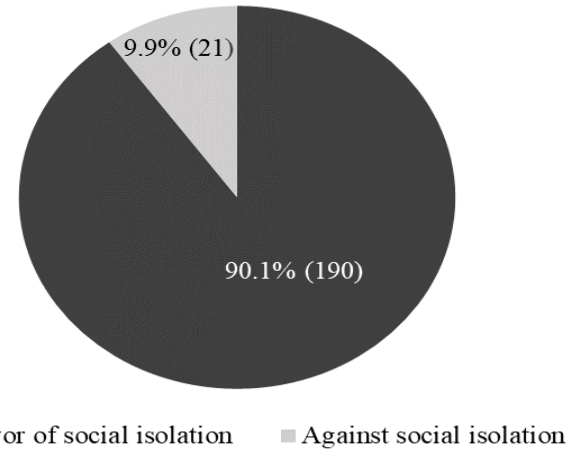

Figure 3 Distribution of participants according to their opinion on social isolation (n = 211). Brazil, 2023

In all, 90.1% of participants claimed to be in favor of social isolation, and this percentage increased in participants with tetraplegia (97.1%) but decreased in those with paraplegia (86.2%). An association was observed between opinion on isolation and education (p=0.031, Pearson Chi-square test) and gender (p=0.014, Pearson Chi-square test), indicating that people with higher levels of education and women tended to be more favorable towards social isolation. Regarding the benefits of isolation, 75.8% perceived the benefits, while 24.2% did not recognize these benefits.

Regarding prevention measures imposed by the pandemic, 92.4% said they were able to remain socially isolated, while 7.6% (16) reported they were unable to remain socially isolated. Of these, 62.5% (10) said they had to work, 12.5% (2) reported living alone and 25.0% (4) reported other reasons for being unable to remain socially isolated.

Table 2 shows the measures adopted by the participants to prevent coronavirus infection. (Table 2)

Table 2 – Distribution of participants according to the prevention measure adopted to prevent COVID-19 (n=211). Brazil, 2023

Prevention	Frequency	Percent %
Disinfection with hand sanitizer	176	83.4
Hand washing	169	80.1
Physical distancing (hugs, kisses and touch)	163	77.2
Staying at home	159	74.9
Face mask	151	71.6
Healthy diet	101	47.9
Disinfecting groceries	99	46.9
Disinfecting cell phones and the home	93	44.1

Staying in the sun	80	37.9
Sleep	80	37.9
Increased wheelchair sanitizing	65	30.8
Physical exercise	58	27.5
Vitamin supplements	57	27.0
No prevention measures	1	0.5
Other	4	1.9
Total respondents		211

The use of hand sanitizer, hand washing, physical distancing (avoiding hugs, kisses and handshakes), staying at home and wearing a face mask were the preferred COVID-19 prevention methods for more than 70% of participants. Only one participant stated that they did not take any prevention measure. Increased wheelchair sanitizing was reported by only 30.8% of participants. The following table shows the most common feelings experienced by the participants in their daily lives since the start of the coronavirus/COVID-19 pandemic. (Table 3)

Table 3 – Distribution of participants according to the feelings experienced since the emergence of the COVID-19 pandemic (n=211). Brazil, 2023

Feeling	Frequency	Percent %
Faith	132	62.6
Hope	129	61.1
Solidarity, compassion	127	60.2
Anxiety	97	46.0
Uncertainty	95	45.0
Courage	72	34.1
Fear	72	34.1
Love	61	28.9
Anguish	58	27.5
Sadness, melancholy	44	20.8
Joy, happiness	25	11.8
Wanting to die	10	4.4
Other	8	3.8
Total respondents		211

The most common feelings among the participants were faith, hope and solidarity/compassion. In all, 85.8% (181) of the participants experienced a positive feeling and 71.1% (150) experienced a negative feeling, while 59.0% (122) reported they had both positive and negative feelings during the pandemic. Figure 4 shows the participants' view of the world after the pandemic, that is, whether they believe it will improve, worsen or remain the same. (Figure 4)

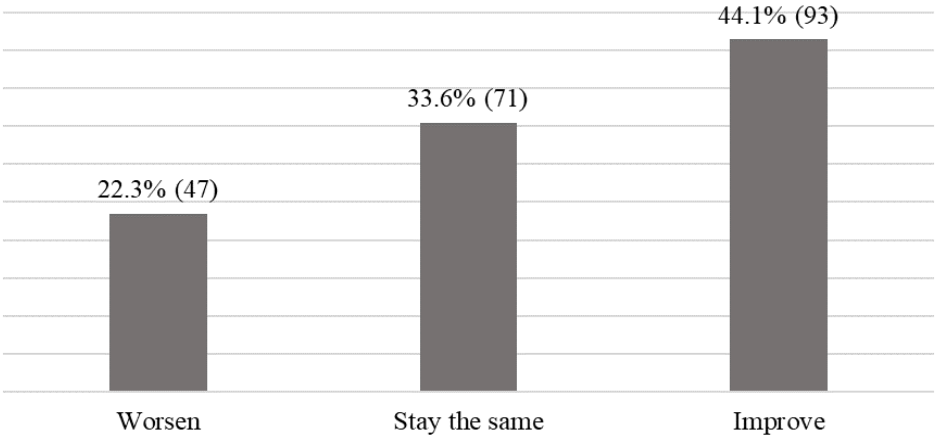

Figure 4 - Distribution of participants regarding their view of the world after the COVID-19 pandemic (n=211)
Source: Author

It is noted that the majority of participants (55.9%) believe that the world will remain the same or worsen after the COVID-19 pandemic. Moreover, 85.8% (181) of the participants claimed they have experienced some difficulty since the pandemic began. The reported difficulties are listed in Table 4. (Table 4)

Table 4 – Difficulties experienced since the start of the COVID-19 pandemic (n=211). Brazil, 2023

Difficulty	Frequency	Percent %
Social isolation	69	32.7
Maintaining therapy	51	24.2
No difficulty	30	14.2
Physical distancing	22	10.4
Fear of contamination	17	8.1
Financial	14	6.6
Hygiene	14	6.6
Leisure	11	5.2

It is evident that isolation represents the greatest difficulty reported by the participants; moreover, difficulties related to locomotion were mentioned by 3.4% of participants, while dependence and information were reported by 1.9% of respondents in each of the categories. Regarding the difficulties indicated since the onset of the pandemic, the responses between the men and women differed (p=0.025, Pearson's Chi-squared test); 37.9% of men indicated difficulty since the pandemic began versus 22.5% of women.

Discussion

The participants were predominantly adult men who were economically active before SCI, as already observed in previous studies.[13,14]. The mean age of 41.48 years shows a slight aging of this population in Brazil, following the global

trend.[13] Currently, longitudinal studies have accompanied the aging of people with SCI, since the older the individual at the time of injury, the faster the physical decline in later years, which alters the rehabilitation process and increases social and economic costs.[14,15]

Regarding the level of the lesion, paraplegia predominated. This data corroborates other findings described in the national and international literature.[16,17] However, these findings are not homogeneous since some studies indicate a larger number of people with traumatic SCI at cervical level with tetraplegia.[17,18] The level of SCI directly influences the severity of the SCI sequelae, which increases the need for help from caregivers with daily activities and hinders social isolation in some cases.[7]

The social profile of the participants of this study shows that people with higher levels of education and who come from the so-called richer regions in Brazil, can participate more easily in online research surveys. On the other hand, even with a higher level of education than the population in general, income remains low and financial dependence on government aid is high. These data reveal the need for investments in the rehabilitation of people with SCI to ensure they can return to adapted work and increase their income and financial independence, especially at a time of global financial crisis and growing unemployment rates in Brazil.[13,15,16] It is also essential to consider the inclusion of people with disabilities in the job market, especially in the economic recovery plans after the crisis associated with the COVID-19 pandemic.

In addition, it is expected that people with quadriplegia require more care for their daily activities. This result highlights the need for actions to combat the spread of coronavirus in people with disabilities and their caregivers, who may be family members or hired professionals. These data corroborate those of a study that identified a greater need for caregivers among people with high cervical or thoracic injuries, given their greater vulnerability to the effects of COVID-19. As such, some educational materials have been made available to the Brazilian population.[19,20]

Regarding the access to information about COVID-19, the findings showed that television journalism in Brazil has actively provided information and guidelines to viewers, with a predominance of information on the pandemic on the schedule of most terrestrial television networks. In addition, the Internet, through social media, websites and messaging applications, has shown its potential for the provision of information to the Brazilian population.

In spite of the extensive disclosure of health-related information in the media, some researchers are concerned about the quality, clarity and veracity of this information, especially among vulnerable populations such as people with disabilities[9]. Although social media and messaging applications may optimize the disclosure of relevant information, they are also important for the spread of fake news. The lack of knowledge on the disease itself and the resulting doubts and uncertainties create a favorable scenario for the dissemination of false and low-quality information.[21,22]. A Chinese study conducted during the COVID-19 outbreak showed a high prevalence of mental health problems positively

associated with the frequency of exposure to social media.[22] As such, in Brazil, some actions have been taken to ensure quality health-related information and to combat fake news, such as the information website for people with disabilities called D+information (demaisinformacao.com.br), as well as other initiatives.[23]

Most of the participants reported they were in favor of social isolation, especially those who had tetraplegia. This result may be related to the level of social participation of people with disabilities who, due to the lack of accessibility and existing architectural barriers, have already found themselves distanced from social activities.[24] Thus, social isolation is an everyday experience for many of the people with SCI in Brazil and requires greater attention and investment for effective changes to occur. An interesting finding was the tendency of participants with higher level education and women to be more favorable towards social isolation. This data can be interpreted in light of previous studies that show the greater involvement of women with health care and the effect of education level on most health-related results.[25]

Although most of the participants perceived the benefits of social isolation in controlling the COVID-19 pandemic, the percentage of those who did not recognize these benefits (24.0%) was higher than that of those who were against isolation (9.9%). This contradiction may signal a lack of understanding of the provided information and the need for investments in effective health education for this population, such as initiatives with the use of remote rehabilitation.[10,26] Regarding the isolation imposed by the pandemic, although most participants reported they were able to maintain isolation, the following data reveal the emotional challenges and main difficulties reported on performing prevention measures, including isolation.

Regarding the prevention measures for COVID-19, the results showed that adherence may reflect the access to information about the pathology, reinforcing the relevance of health education in social media and combating the dissemination of misinformation and fake news. In this sense, laws are needed to regulate the use of personal data and the implementation of social media surveillance systems, since they are important sources of health-related information and can contribute or hinder the control of the outbreak of COVID-19.

Despite the efforts of the scientific community and the press, there is still a lot of misinformation regarding the novel coronavirus. Therefore, every responsible initiative to divulge scientific information is positive, such as the *Covid Verificado* platform, developed by researchers at the University of São Paulo to scientifically verify data related to COVID-19.[27] In addition to the prevention measures indicated by the participants, most people with SCI need to sanitize their wheelchairs. In any case, it should be noted that one form of contagion is contact with contaminated surfaces and objects[28] and the wheelchair, as one such form of contamination, should be sanitized more frequently during the pandemic.[29]

Regarding participants' most frequent feelings during the pandemic, findings highlighted that to analyze the individual in a pandemic situation, it is important to understand that it can lead to feelings of stress and anxiety; however, with

positive psychology, this same situation can also generate a perspective of hope, depending on the event and the individual. Therefore, during the COVID-19 pandemic, ambivalent feelings are expected. Nevertheless, the concerns of people with SCI, which are legitimate and real, should be considered, including vulnerability to infection and fragility in the provision of caregivers.[26]

Although a large percentage of participants (44.1%) said they believe the world will be better after the pandemic, 55.9% believe it will remain the same or worsen after the experience. This feeling may be related to the additional effects of this context, which may include the perception of less social support, separation from loved ones and loss of freedom. Therefore, it is essential for health education to be improved to recognize this period as a potential trigger of negative feelings. Moreover, vulnerable populations should be able to actively consult clinical psychotherapists who can quickly detect warning signs.[30]

The greatest difficulty indicated by the participants was social isolation itself (32.7%), followed by difficulty in maintaining therapies (24.2%). Isolation can cause widespread loneliness and boredom, which often affects the individual's physical and mental well-being, besides generating anguish and frustration.[30] Therefore, it is essential to monitor the feelings expected to occur as a result of the current context, so they do not become pathological, especially in people with SCI requiring inclusion support actions. Regarding the maintenance of therapies, remote support experiences already existing in Brazil and remote rehabilitation programs have been recommended by specialists and may serve as an alternative.[10]

Finally, an individualized look at this population during the pandemic is essential since, before the pandemic, they already faced limiting social conditions compared to the population in general. Moreover, it should be highlighted that there is a possibility of neglect of care for people with disabilities in times of crisis,[26] thus reinforcing the critical need to consider the specific characteristics of this population.

Study limitation

This study reveals relevant data on the particularities of the experience of people with SCI during the COVID-19 pandemic in Brazil. However, it has some limitations inherent in the collection of cross-sectional data in a virtual environment. Future studies may consider longitudinal follow-up and telephone interviews, with a representative sample in all Brazilian regions, in addition to the Southeast and the South. Another limitation is the non-participation of people with SCI who do not have Internet access or who have a physical limitation in handling equipment with internet access, which is common among people with SCI tetraplegia in Brazil.

Conclusion

The present study showed that people with SCI in Brazil have faced great challenges during the COVID-19 pandemic. However, access to health information has had a positive impact on the adoption of key measures to prevent infection by

the novel coronavirus. The data presented here also indicate the need to consider the emotional aspects involved in social isolation, revealed both in the ambiguous feelings and in the difficulties reported by the participants with SCI during the pandemic, which should be treated as legitimate and real.

Therefore, strategies aimed at health promotion in social media and remote rehabilitation programs should be promoted by professionals. On the other hand, regulation of the virtual environment is required to combat disinformation and fake news, and to protect data, especially for more vulnerable populations such as people with disabilities.

Statement of Ethics

The study was approved by the ethics committees of the Ribeirão Preto College of Nursing at University of São Paulo, under protocol nº CAAE: 07355319.9.0000.5393.

Conflicts of Interest

The authors declare that they have no conflict of interest.

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