

## Brief Report

# The effect of the COVID-19 pandemic on the health-related quality of life in home-based patients with spinal cord injuries in Japan

**Mihoko Matsuoka, Mikio Sumida**

Department of Rehabilitation Medicine, Aijikai Rehabilitation Hospital, Osaka, Japan

**Context:** The COVID-19 pandemic has forced people to maintain social distance and to refrain from going out. As a result, home-based patients with spinal cord injuries (SCI) are not only less able to go out, but they may have difficulty in easily receiving long-term care services. There are concerns that their health-related quality of life (HRQOL) may have deteriorated. We aimed to clarify the effect of the COVID-19 pandemic on HRQOL in home-based patients with SCI.

In June 2020, when the COVID-19 pandemic was finally settling down in Japan, we conducted a mail survey of 266 patients with SCI regarding changes in the frequency of going out, the long-term care services, and their HRQOL due to the COVID-19 pandemic. They had all been discharged from our hospital (Rehabilitation medical center) by 2019, and were expected to be living at home. We received answers from 135 patients about their HRQOL.

**Findings:** Respondent characteristics indicated that many of them were elderly (74.1% were over 60 years of age) and many had cervical SCI (70.5%). Worsened HRQOL since the impact of the COVID-19 pandemic was reported by 40% of respondents. The most commonly reported dimension was pain/discomfort. Significantly, many had been injured comparatively recently and had reduced frequency of going out and receiving home-visit nursing or rehabilitation services than patients whose HRQOL was unchanged.

**Conclusion/ Clinical Relevance:** This study clarifies the negative effect of the COVID-19 pandemic on HRQOL in home-based patients with SCI. Many respondents had worsened HRQOL, in particular pain/discomfort. It was suggested that the decrease in the frequency of going out may be one of the factors that affected the deterioration of their HRQOL.

**Keywords:** Spinal cord injury, COVID-19, Health-related quality of life, Pandemic, Home-based patients

## Introduction

The COVID-19 pandemic has forced individuals to refrain from going out. To prevent the spread of infection, guidelines recommend following hand washing etiquette, maintaining a sufficient distance from others (social distancing), and wearing appropriate personal protective equipment, such as masks. Within this context, home-based patients with spinal cord injuries (SCI) may be not only less able to go out, but may have difficulty in easily receiving long-term care services. Furthermore, maintaining a social distance may be hard for those who need physical care. Therefore we theorized that their health-related quality of life

(HRQOL), which was low even in usual times,<sup>1,2</sup> may have deteriorated. This study aimed to clarify the effect of the COVID-19 pandemic on HRQOL in home-based patients with SCI.

## Materials and methods

We conducted a mail survey in June 2020, approximately two months since a period of national state of emergency had been declared in Japan. Under the state of emergency in Japan, each prefectural governor could only request the residents to cooperate in preventing infections, including refraining from going out except when necessary to maintain their livelihoods. We included patients with SCI, who had undergone inpatient rehabilitation treatments at our hospital, were discharged from 2012 to 2019, and

Correspondence to: Mihoko Matsuoka, Department of Rehabilitation Medicine, Aijikai Rehabilitation Hospital, 5-7 Hakubai-Cho, Takatsuki City, Osaka 569-1116, Japan; Ph: +81-72-683-1212. Email: matsuoka\_mihoko@yahoo.co.jp

were expected to be living at home. We excluded patients who were admitted to other hospitals or facilities, were confirmed dead, had unknown current addresses, or had previously refused to participate in other mail surveys. A total of 266 patients were listed.

The questionnaire consisted of three parts. The first part was about their characteristics, such as sex, age, years since injury, cervical or thoracic/lumbar SCI, pedestrian or wheelchair user, and disability grade. The second part concerned changes due to the COVID-19 pandemic in the frequency of going out, in outpatient care services, in medical treatment, in home-visit nursing or rehabilitation services, and in home-visit caregiver services. The third part of the questionnaire was about changes in respondent's HRQOL since the domestic onset of the COVID-19 pandemic in January 2020. We used the Japanese version of the five-level EQ-5D (EQ-5D-5L). The EQ-5D is a family of instruments to describe and value health, and has been used in a wide range of conditions and population. The EQ-5D-5L has been translated into Japanese.<sup>3</sup>

This study was approved by Aijinkai Rehabilitation Hospital Ethics Committee, and respondents answered the questionnaire anonymously. We did not specify survey fillers who represented the patients when they could not write it by themselves. Statistical analysis was performed by using Fisher's exact test and  $\chi$ -square test by the Easy-R analysis software (The R Foundation for Statistical Computing, Vienna, Austria). We considered a *P* value of <0.05 to be significant.

## Result

We received responses from 146 of the patients within the deadline. Six patients had been admitted to other hospitals or facilities and another five patients responded with blank answers to the entire questionnaire or to the section concerned with changes of HRQOL. We, therefore, obtained valid answers about HRQOL from 135 patients (50.8%).

### Participant characteristics

Table 1 shows the characteristics of the participants; 95 cases (70.9%) were male and 79 patients (70.5%) had cervical SCI. At their current age, 100 patients (74.1%) were over 60 years old. The most commonly reported period in years since injury was about four years, accounting for 70.2% that answered five years or less. The number of non-wheelchair users (both indoors and outdoors) was the same as the

**Table 1 Study group characteristics.**

Variable	N (%)	Missing (blank) (%)
Male: Female	95 (70.9): 39 (29.1)	0.7
Level of SCI	112	17
Cervical	79 (70.5)	
Thoracic/lumbar	28 (25.0)	
Other*1	5 (4.5)	
Current age		
10s (18 years or order)	2 (1.5)	
20s	4 (3.0)	
30s	3 (2.2)	
40s	8 (5.9)	
50s	18 (13.3)	
60s	26 (19.3)	
70s	47 (34.8)	
80s	24 (17.8)	
90s	3 (2.2)	
Years since injury	131	3
1y	14 (10.7)	
2y	18 (13.7)	
3y	18 (13.7)	
4y	24 (18.3)	
5y	18 (13.7)	
6y	9 (6.9)	
7y	7 (5.3)	
8y	9 (6.9)	
9y	3 (2.3)	
10y and over	11 (8.4)	
Mobility	131	3
Non-w/c user indoors and outdoors	51 (38.9)	
Non-w/c user indoors but w/c user outdoors	29 (22.1)	
w/c user indoors and outdoors	51 (38.9)	
Disability grade specified by the Ministry of Health and Welfare of Japan	131	3
Level 1.2 (severe)	88 (67.2)	
Level 3.4.5 (mild)	15 (11.5)	
No acquisition	28 (21.4)	

SCI: spinal cord injury, w/c: wheelchair

\*1: Two answered 'spinal cord infarction', one answered 'spinal cord injury', one answered 'other' but the content was not written, and one chose both cervical and thoracolumbar spinal cord injury.

wheelchair users (both indoor and outdoor): 51 each (38.9%).

### Changes in the frequency of going out and services

We asked about changes in the frequency in three options: decrease, unchangeable, and increase. Since we did not set the 'no use' option, it is presumed that those who had not used it before left the answer blank. Decreased frequency was reported by 30.8% of respondents for going out, 26.0% for outpatient care services, 19.2% for medical treatment by their doctors, 10.0% for home-visit nursing or rehabilitation, and 4.0% for home-visit caregiver services (Table 2).

**Table 2** Changes in the frequency of going out and service.

Variable	N (%)	Missing (blank) N(%)
Going out	133	2 (1.5)
Decrease	41 (30.8)	
Unchangeable	90 (67.7)	
Increase	0	
Other*1	2 (1.5)	
Outpatient care service	104	31 (23.0)
Decrease	27 (26.0)	
Unchangeable	75 (72.1)	
Increase	2 (1.9)	
Other	0	
Medical treatment by medical doctor	125	10 (7.4)
Decrease	24 (19.2)	
Unchangeable	99 (79.2)	
Increase	2 (1.6)	
Other	0	
Home-visit nursing or rehabilitation	100	35 (25.9)
Decrease	10 (10.0)	
Unchangeable	87 (87.0)	
Increase	0	
Other*2	3 (3.0)	
Home-visit caregiver service	75	60 (44.4)
Decrease	3 (4.0)	
Unchangeable	69 (92.0)	
Increase	3 (4.0)	
Other	0	

\*1: Both answered that they had not gone out before. \*2: One answered that the frequency of home-visit nursing did not change, but home-visit rehabilitation decreased. One answered that the frequency of home-visit nursing increased, but home-visit rehabilitation decreased. One answered that it was considering their use.

### Changes in their HRQOL

The EQ-5D-5L essentially consists of the EQ-5D descriptive system and the EQ visual analogue scale (EQ VAS). The descriptive system comprises five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). In 40% of respondents (54 cases) worsening was reported within at least one dimension compared to prior to the domestic onset of the COVID-19 pandemic in January 2020. The most common dimension that became worse was pain/discomfort (37 cases, 68.5%), followed by mobility (29 cases, 53.7%), usual activities (27 cases, 50.0%), anxiety/depression (24 cases, 44.4%), the EQVAS (23 cases, 42.6%), and then self-care (7 cases, 13.0%).

**Table 3** Factors for worsening health-related quality of life.

	Deterioration group N=54	Invariant group N=79	P value
Male: Female	34: 20	61: 19	0.096
Cervical: thoracic/ lumbar	34: 12	45: 16	0.986
Current age			0.358
Under 60s: over 70s	27: 27	34: 47	
Years since injury			<0.001
Under 5y: over 6y	42: 10	50: 29	
Pedestrians: w/c user (indoor)	30: 23	50: 28	0.387
Pedestrians: w/c user (outdoor)	16: 37	35: 43	0.090
Severe physical disabilities: others	39: 12	49: 31	0.070
Going out			<0.001
Unchangeable: decrease	25: 27	65: 14	
Outpatient care services	27: 12	48: 15	0.438
Unchangeable: decrease			0.838
Medical treatment			
Unchangeable: decrease	39: 10	60: 14	
Home-visit nursing or rehabilitation	31: 8	56: 2	0.013*
Unchangeable: decrease			

Data are shown as the number of case.

SCI: spinal cord injury, w/c: wheelchair \*: Fisher's exact test, others are  $\chi$ -square test.

### Factors that worsened HRQOL

The deterioration group includes the 54 respondents that answered that one or more dimensions were worse. The invariant group, meanwhile, includes 81 respondents. These two groups, their characteristics and the changes in frequency are shown in Table 3. The deterioration group showed significantly fewer years since injury, more decreases regarding going out, and were more likely to decrease home-visit nursing or rehabilitation. Notably, 65% of those who reduced their going out had worsened HRQOL, while those who had no change to their going out were only 27.8% worse.

### Discussion

We conducted a mail survey to clarify the effect of the COVID-19 pandemic on the HRQOL of home-based patients with SCI. First, 40% of them had worsened HRQOL. In the general population, there have been reports of decreased mental health and quality of life (QOL). For example, in a report from Austria, depressive symptoms were 21% higher and anxiety symptoms were 19% higher since the onset of the COVID-19

pandemic compared with previous epidemiological data.<sup>4</sup> In a report from Cyprus, 66.7% reported significant changes to their QOL.<sup>5</sup> In these two and other papers, people with decreased mental health and QOL had common characteristics. Female sex, unemployment status, low income have all been reported as high-risk factors.<sup>4-7</sup> Many of our surveyed patients were male, in contrast with the literature, but 40% of them had poorer HRQOL. This result is one of the specificity of this research.

In two surveys of patients with chronic diseases, the QOL was not reported to have worsened. The QOL of patients with multiple sclerosis was reported to be higher according to the satisfaction with sexual life and social function subscales than before the COVID-19 pandemic.<sup>8</sup> This result of patients with multiple sclerosis might be because their average age was younger (37.5 years old) and there were more women, unlike in our study. Next, the QOL of patients with cancer during the COVID-19 pandemic were not lower scores, but multivariate analysis demonstrated that being 'concerned about contracting coronavirus' was correlated with lower QOL and emotional functioning score.<sup>9</sup> From this result, we can surmise that while those with chronic illnesses may not have significant changes in QOL, there remains heightened concern about contracting the virus. It is natural that they were worried, because elderly people with comorbidities are more likely to become seriously or fatally affected by COVID-19.

Our most commonly reported worsened dimension was pain/discomfort. The risk of worsening pain/discomfort has been associated with aging, chronic disease, lower income, epidemic effects and worries about becoming infected with COVID-19.<sup>10</sup> Our findings are similar to this report, because many of our target patients were elderly, all had chronic disease (SCI), and were also probably worried about becoming infected.

The decrease in the frequency of going out affected the deterioration of our patient's HRQOL. Elderly people have been reported to need to contact or to eat with others, and social participation at least once a week while social distancing, even during the COVID-19 pandemic, from the perspective of dementia, functional disability, depression, and premature death.<sup>11</sup> Meanwhile, using the internet might be useful in facilitating social participation without the same risk of transmission of COVID-19. Since the COVID-19 pandemic, the Government of Japan has recommended several ways using the internet, such as homecoming via video calls, online drinking parties, and

telemedicine, as methods to reduce direct contact with others. To maintain the HRQOL of many elderly patients with SCI, they are recommended to participate in society using videos via the internet if possible. Moreover, preparation of the environment so it can be used more easily, and rehabilitation training have also been suggested, because many patients with cervical SCI also have disabilities related to use of their fingers.

The present study had some limitations. It was a single hospital study, so the number of patients was limited. Many of our target patients were men and elderly, had cervical SCI, and had been injured for a short period of time. These characteristics are similar to those of recent trends within patients with SCI in Japan.<sup>12</sup> With the rise of Japanese aging population, the rate of cervical SCI and incomplete injury by fall has been increasing.<sup>12,13</sup> Our patients can therefore be thought to be representative of Japanese patients with SCI. A second limitation is that the Japanese government only requested refraining from going out and from opening stores between April and May 2020. In Osaka, where our hospital is located, the governor ordered the closure of schools and some shops as soon as possible, but the policy was not as restrictive as lockdown in some other countries. Finally, this study is not a prospective cohort study. When the COVID-19 pandemic partially subsided in June 2020, we asked the patients for a subjective comparison with the period before the pandemic, so there are issues with accuracy. It may be important to investigate our target patients' HRQOL on a more regular basis to ascertain whether the responses were truly reflective of the conditions at the time of observation.

In summary, this study clarified the effect of the COVID-19 pandemic on the HRQOL in home-based patients with SCI. We showed that 40% of respondents had worsened reported HRQOL, in particular regarding pain/discomfort. There was also decrease in the frequency of going out, which affected the deterioration of their HRQOL.

## Acknowledgements

We thank Benjamin Phillis for editing the article.

## Disclaimer statements

**Contributors:** None.

**Funding:** None.

**Conflicts of interest:** Authors have no conflict of interests to declare.

## References

- 1 Migliorini CE, New PW, Tonge BJ. Quality of life in adults with spinal cord injury living in the community. *Spinal Cord* 2011 Mar;49(3):365–70. doi:10.1038/sc.2010.102. Epub 2010 Aug 10. PMID: 20697422
- 2 Barclay L, New PW, Morgan PE, Guilcher SJT. Satisfaction with life, health and well-being: comparison between non-traumatic spinal cord dysfunction, traumatic spinal cord injury and Australian norms. *Spinal Cord Ser Cases* 2019 May 23;5:50. doi:10.1038/s41394-019-0193-9. eCollection 2019. PMID: 31632708
- 3 Shiroiwa T, Ikeda S, Noto S, Igarashi A, Fukuda T, *et al.* Comparison of value Set based on DCE and/or TTO data: scoring for EQ-5D-5L health states in Japan. *Value Health* 2016 Jul-Aug;19(5):648–54. doi:10.1016/j.jval.2016.03.1834. Epub 2016 Apr 26. PMID: 27565282
- 4 Pieh C, Budimir S, Probst T. The effect of age, gender, income, work, and physical activity on mental health during coronavirus disease (COVID-19) lockdown in Austria. *J Psychosom Res* 2020 Sep;136; doi:10.1016/j.jpsychores.2020.110186. Epub 2020 Jul 3. PMID: 32682159
- 5 Solomou I, Constantinidou F. Prevalence and predictors of anxiety and depression symptoms during the COVID-19 pandemic and compliance with precautionary measures: age and sex matter. *Int J Environ Res Public Health* 2020 Jul 8;17(14). doi:10.3390/ijerph17144924. PMID: 32650522
- 6 Teotonio I, Hecht M, Castro LC, Gandolfi L, Pratesi R, Nakano EY, *et al.* Repercussion of COVID-19 pandemic on Brazilians' quality of life: a nationwide cross-sectional study. *Int J Environ Res Public Health* 2020 Nov 18;17(22). doi:10.3390/ijerph17228554. PMID: 33218087
- 7 Pieh C, Budimir S, Delgado J, Barkham M, Fontaine JR, Probst T. Mental health during COVID-19 lockdown in the United Kingdom. *Psychosom Med*. 2020 Oct 1. doi:10.1097/PSY.0000000000000871. Online ahead of print. PMID: 33009276
- 8 Capuano R, Altieri M, Biseco A, d'Ambrosio A, Docimo R, Buonanno D, *et al.* Psychological consequences of COVID-19 pandemic in Italian MS patients: signs of resilience? *J Neurol*. 2020 Jul 28; 1–8. doi:10.1007/s00415-020-10099-9. Online ahead of print. PMID: 32725312
- 9 Jeppesen SS, Betsen KK, Jorgensen TL, Holm HS, Holst-Christensen L, Tarpgaard LS, *et al.* Quality of life in patients with cancer during the COVID-19 pandemic - a Danish cross-sectional study (COPICADS). *Acta Oncol* 2021 Jan;60(1):4–12. doi:10.1080/0284186X.2020.1830169. Epub 2020 Oct 8. PMID: 33031010
- 10 Ping W, Zheng J, Niu X, Guo C, Zhang J, Hui Y, *et al.* Evaluation of health-related quality of life using EQ-5D in China during the COVID-19 pandemic. *PLoS One* 2020 Jun 18;15(6):e0234850. doi:10.1371/journal.pone.0234850. eCollection 2020. PMID: 32555642
- 11 Kimura M, Ojima T, Ide K, Kondo K. Allaying post-COVID19 negative health impacts among older people: the “need to do something with others” -lessons from the Japan gerontological evaluation study. *Asia Pac J Public Health* 2020 Nov;32(8):479–84. doi:10.1177/1010539520951396. Epub 2020 Sep 16.
- 12 Miyakoshi N, Suda K, Kudo D, Sakai H, Nakagawa Y, Mikami Y, *et al.* A nationwide survey on the incidence and characteristics of traumatic spinal cord injury in Japan in 2018. *Spinal Cord*. 2020 Aug 11. doi:10.1038/s41393-020-00533-0. Online ahead of print.
- 13 Tafida MA, Wagatsuma Y, Ma E, Mizutani T, Abe T. Descriptive epidemiology of traumatic spinal injury in Japan. *J Orthop Sci* 2018 Mar;23(2):273–6. doi:10.1016/j.jos.2017.10.013. Epub 2017 Nov 14. PMID: 29150193