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The impact of the COVID-19 pandemic on physical activity and associated technology use in persons with multiple sclerosis: an international RIMS-SIG Mobility survey study.

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Highlights

- PwMS reduced physical activity (PA) during the COVID-19 pandemic.
- Intensity of PA at moderate and high levels decreased the most during the pandemic.
- Walking was the PA most frequently performed and increased significantly during the pandemic.
- 31% of inactive PwMS had no intention of changing PA behaviour post-pandemic.
- Wearables were the most frequently used technology during the pandemic.

Abstract

Objective. To investigate the impact of the COVID-19 pandemic on physical activity (PA) in persons with multiple sclerosis (PwMS).

Design and Setting. A multi-centre international online survey study was conducted within 11 participating countries. Each country launched the survey using online platforms from May to July 2021.

Participants. This was an electronic survey study targeting PwMS.

Intervention. Not applicable.

Outcome measures. The survey ascertained PA performance and its intensity, the nature of the activities conducted and the use of technology to support home-based physical activity before and during the pandemic.

Results. 3725 respondents completed the survey. Pre-pandemic, the majority (83%) of respondents reported being physically active, and this decreased to 75% during the pandemic. This change was significant for moderate and high intensity activity ($p < .0001$). Activities carried out in physiotherapy centres, gyms or pools decreased the most. Walking was the most frequently performed activity pre-pandemic (27%) and increased during the pandemic (33%).

24% of those inactive during the pandemic had no intention of changing their PA behaviour post-pandemic. 58% of the respondents did not use technology to support PA during the pandemic. Of those who did use technology, wearables were most used (24%). Of those currently non-active (25%) expressed a preference for an in-person format to conduct PA post-pandemic.

Conclusion. PA performance, especially activities at moderate and high intensities, decreased during the pandemic in PwMS compared to pre-pandemic. Walking and using wearables gained popularity to stay active. As we move towards an endemic-COVID-19, a call for action to develop interventions focused on walking programmes, with specific emphasis on increasing PA of persons with MS is proposed.

Keywords Persons with Multiple Sclerosis, COVID-19 pandemic, physical activity, technology, walking, wearables

Abbreviations

Persons with multiple sclerosis (PwMS)

Primary investigator (PI)

Special Interest Group for Mobility (SIG Mobility)

Rehabilitation in Multiple Sclerosis (RIMS)

Introduction

Physical activity is associated with a wide range of benefits for physical and mental outcomes and secondary disease prevention^{1, 2}. For persons with multiple sclerosis (PwMS), an extensive body of literature reports evidence for the benefits of physical activity on walking³, fatigue⁴ and quality of life⁵ in PwMS. Concerningly, PwMS are less physically active compared to the general population⁶, and this may have been further reduced during the COVID-19 pandemic^{7, 8}.

National and local restrictions aiming to slow down the spread of COVID-19 forced many venues offering physical activity to close⁷, reducing the availability of physiotherapy and exercise services, and thus possibly decreasing the level and type of physical activity for individuals with MS. In the general population and in people living with disabilities there is emerging evidence that the Covid-19 pandemic has negatively impacted physical activity behavior⁷⁻¹¹. There is, however, a lack of knowledge regarding whether the COVID-19 pandemic has influenced physical activity in individuals with MS compared to pre-pandemic times.

Due to COVID-19 restrictions, rehabilitation services often transitioned to a virtual environment heavily reliant on technology at the beginning of the pandemic and progressed to a blended environment as restrictions were eased. Pre-pandemic, there was limited use of technology for physical activity promotion in clinical settings, despite several studies supporting technology-based interventions^{12, 13}. It is unclear how and whether technology was used by PwMS for performing physical activity during the pandemic.

The Special Interest Group for Mobility (SIG Mobility) of the Rehabilitation in Multiple Sclerosis (RIMS) network launched this international survey study which aimed at investigating whether and how physical activity carried out by PwMS may have changed during the COVID-19 pandemic. In this current paper, we describe the levels of physical activity and its intensity, the nature of the activities conducted and the use of technology to support physical activity as reported by PwMS before and during the COVID-19 pandemic.

Material and Methods

The CHERRIES reporting guideline for online surveys¹⁴ was used to inform the conduct and reporting of this study.

Design. This was an electronic survey study targeting PwMS. Ethical approval to conduct the study was obtained from all participating institutions, and all respondents provided their informed consent electronically prior to commencing the survey. No identifiable personal data was collected from the survey. A primary investigator (PI) was identified for each country, and a project coordinator was assigned. The PI was locally responsible for all the project phases as well as to ensure communication with the local project partners, the other PIs and the project coordinator.

Development and pre-testing. The study was initiated by the SIG Mobility group of the RIMS. Physiotherapists and researchers from eleven countries (centres/institutes/individuals) agreed to participate: Australia, Belgium, Czech Republic, Ireland, Israel, Italy, Norway, Serbia, Spain, Turkey and United Kingdom.

Development. A small working group of PI's drafted the first version of the survey based on previous work⁸ and extensive expertise. File sharing on Google Drive and regular discussion meetings with the project PIs enabled shared online working. During January and February 2021 input from all project partners were accounted for to improve the content and focus of the survey. The English-language version of the survey was piloted with PwMS in four countries for usability and clarity. The surveys were then translated into the national language of the participating countries and transferred into an online survey platform. The following platforms were used across the 11 countries: Survey Monkey, Qualtrics, Google Forms, Corporater Surveyor, Eusurvey, onlinesurveys.ac.uk and RedCap. Additional pilots were conducted by all project PIs to explore usability and technical functionality of the individual platforms at country level.

The final survey consisted of 74 questions, and took approximately 30 minutes to complete. Response options included multiple choice and open-ended answers. The latter was not the case in Norway due to their ethics requirements. The complete survey as well as the coding methodology of the variables applied can be found as Supplementary Table 1. This paper reports on the following information which were collected in the survey:

- Descriptive information such as country of participation, age, gender, years since diagnosis, patient determined disease steps scale and local restrictions due to pandemic aimed at slowing the spread of COVID-19.
- Self-reported physical activity participation which included type and intensity of physical activity; type of technology used to perform physical activity both prior to COVID-19 and at the time of the survey, i.e. during the pandemic.
- Intention to change physical activity participation and preferred mode of performing physical activity once restrictions are removed.

- Perceived positive and negative aspects of home-based physical activity using technology.

The following explanations were provided to define physical activity and intensity in the survey.

Physical activity. ‘Physical activity includes activities you do at work, as part of your house and garden work, to get from place to place, and in your spare time for recreation, exercise or sport. It also includes rehabilitation or exercise led by your physiotherapist in person or using technology, doing a home programme provided by a physiotherapist or other professional. It also includes activities such as walking, gardening, sports, fitness classes, going to the gym, Pilates, yoga, home exercises and dance. It also includes active travel such as cycling or walking to work’.

Intensity. Light - you can do this activity and sing a song, moderate - you can do this activity and have a conversation but not sing, strenuous - you can only utter a few words while doing this activity.

Recruitment. For each country, the PI was responsible for sending the online surveys to their respective recruitment channels, and for collating responses. The recruitment channels comprised of local MS centres and hospitals (through websites, social media and direct mailing to neurologists), national MS registries, physiotherapy MS associations, neurologists and networks involved in MS research or clinical care, as well as the PI’s or national MS organisations professional social media (LinkedIn, Facebook, Instagram, Twitter).

Data collection. Each country launched the survey for a total duration of 6 weeks from May to July 2021. PIs' had the possibility of sending a reminder every 2 weeks if it was feasible within their respective recruitment channels.

Statistical analysis

Survey questions which involved perceived ratings are reported as the percentage proportion of the responses.

The McNemar test was applied to determine whether significant differences exist between the proportion of respondents taking part in physical activity before the pandemic and at the time of completing the survey (during the pandemic). The Chi-square test was applied to determine whether significant differences exist in proportions of responders on: physical activity intensity (light, moderate and high) across time and physical activity type across the 16 listed physical activities across time. All analyses were conducted using the statistical software JMP Pro 15 (SAS Institute Inc., Cary, NC), with a significance level of alpha set at 0.05.

Results

Descriptive information on the responders

In total, data was collected from 11 countries, with a total of 3725 responses which completed the survey: (Australia n= 91, Belgium n= 26, Czech Republic n= 264, Ireland n= 153, Israel n= 52, Italy= 585, Norway = 2218, Serbia n= 27, Spain n= 230, Turkey n= 35, UK n= 44).

Figure 1 shows the percentage distribution of age, the number of years since diagnosis, and the patient determined disease steps scale across the responders. In total, 70% of respondents were female, reflecting the normal distribution of gender in MS¹⁵. Of the total responders, 72% had no local restrictions due to pandemic aimed at slowing the spread of COVID-19 at the time of completing the survey.

Physical activity

Overall, the proportion of responders conducting physical activity at the time of completing the survey was significantly decreased compared to the proportion of responders conducting physical activity before the pandemic; 75% during the pandemic as compared to 83% pre-pandemic ($p < 0.001$).

Intensity of physical activity performance pre-pandemic compared to post-pandemic significantly differed ($X^2(2, 10421) = 36.22, p < 0.0001$). The proportions of responders conducting physical activity at light intensity did not change over time (Pre 10.9%, During 10.5%). However the proportion of responders conducting physical activity at moderate and high intensity decreased at the time of answering the survey compared to pre-pandemic times (moderate: Pre 35.5%, During 27.98%; high: Pre 9.23%, During 5.99%).

The contingency model revealed significant changes (increase or decrease) within the sixteen activities reported ($X^2(15, 10561)=379.27, p<0.0001$). Respondents reported changes in four of the sixteen listed activities, these were: home exercise programmes, exercises in the gym, exercises in water and walking. The changes reflect proportions of respondents changing their activities at the time of completing the survey compared to pre-pandemic times. As seen in Figure 2, There was a 3% increase in respondents participating in physiotherapy home exercise programmes, 6% increase of walking, 7% decrease in exercise in the gym (strength and aerobic exercises), and 3% decrease in exercise in water (e.g. swimming or aqua aerobics).

Reasons to start a new activity or increase physical activity level

The most frequently reported reasons to start a new activity or increase level of physical activity were: more awareness of the public health message to go for a walk and stay active (14%); more time to exercise as there was no travelling to work (6%); more time for physical activity as less time was spent socialising or shopping (6%); more structure and routine in the day (6%); more family and friends support for physical activity (5%).

Reasons to stop or do less physical activity levels

The most frequently reported reasons to stop or do less physical activity were: closed venues (12%); restrictions preventing going to the venue (9%); restrictions preventing exercising in groups (7%); fear of contracting COVID-19 (7%); worsening of MS symptoms (6%); less motivation to exercise (5%); classes were cancelled by the organiser (5%).

Plans to change physical activity post-pandemic

Of the 75% (n=2,756) that were active at the time of survey completion during the pandemic, 44% reported not wanting to change physical activity after restrictions were to be removed, while 33% did want to change physical activity, 22% reported they were unsure if they wanted to make changes when restrictions were lifted. These respondents (of the 75% that were active) had the following preferences to conduct physical activity after COVID-19 pandemic: 31% in-person, 3% remote, 25% mix, 26% no preferences and 15% did not know.

Of the 25% (n=928) that were active pre-pandemic but not at the time of survey completion during the pandemic, 24% reported not wanting to change their physical activity after restrictions were removed, while 31% did want to make changes, and 44% were unsure. These respondents had the following preferences to conduct physical activity after COVID-19 pandemic: 44% in-person, 2% remote, 14% mix, 19% no preferences and 21% did not know of their preferences.

Use of technology

Table 1 provides an overview of the technology used to perform physical activity pre-pandemic and at the time of survey completion, by respondents who were physically active. Table 2 shows the perceived rating of performing home based physical activity using technology.

Discussion

This relatively large international survey study focused in the MS population, found that 83% of respondents reported being physically active pre-pandemic, and this decreased significantly to 75% during the COVID-19 pandemic. Not surprisingly, activities carried out in the

physiotherapy centres, gyms, or pools decreased the most. Walking was the most frequently performed activity pre-pandemic and increased during the pandemic. Concerningly, 31% of those inactive during the pandemic had no intention of changing their physical activity behaviour once restrictions due to the pandemic were lifted, (while 42% were unsure). Two thirds of the respondents (66%) did not use technology aimed to support physical activity during the pandemic. For those who used technology, wearables were the most common device used. Those currently non-active had a preference for an in-person format for physical activity post-pandemic.

Many of our respondents reported being physically active, however, previous studies (pre-pandemic)^{16, 17} indicate that most PwMS are not reaching sufficient levels of physical activity for mental and physical health benefits¹⁸. Thus, our findings of a reduction of physical activity during the pandemic is now of even greater concern.

There is a significant body of evidence of the benefits of physical activity for PwMS for physical and mental health, symptoms and secondary disease prevention^{4, 19, 20}. Therefore, it is concerning that there was a significant reduction of number of people who were physically active during the pandemic. The MS clinical research community needs to turn their attention to re-engaging those persons that ceased being active, in addition to engaging those that were not active at either time point.

There seems to be an opportunity to get people more physically active through engaging in activities of walking, as this was the most frequently performed activity pre- and during the pandemic. There are studies that focus on improving walking outcomes such as speed, distance, kinetics and kinematics, following physiotherapy²¹ and exercise³. However, our

initial scoping search found no studies that solely evaluate walking programmes with a focus on increasing physical activity and meeting the exercise guidelines^{18, 22, 23}. We found only a few studies included walking activity in various forms, but those focused on reducing perceived fatigue^{24, 25}, cardiovascular parameters²⁴ and quality of life²⁶ in MS, while other included walking as an aerobic activity in exercise interventions and programmes²⁷⁻²⁹.

These data suggest that PwMS could potentially favour walking programmes, and as such, paying attention to the impairments underlying walking restrictions in addition to addressing walking as an activity is essential. For example, addressing drop foot or impaired balance by using assistive devices may be important prior to increasing walking distance or intensity³⁰. Addressing these factors will be an essential element of any sustainable programme development in the fluctuating restrictions and uncertainties with COVID-19 becoming endemic in society. We note that fear of contracting COVID-19 was reported as a barrier for physical activity participation, as well as, lack of access to venues and indoor group activities. As we focus on developing interventions to reverse the inactivity during the pandemic, these data suggest that combining education, information-provision and behaviour change techniques with the relevant physical activity will be important.

The format of any future physical activity programme is also an important consideration. Our results suggest that purely technology-based, or remote interventions are not favoured by most PwMS. Those PwMS that continued to be physically active during the pandemic preferred a blended approach, and those persons that were physically inactive preferred an in-person approach. Wearables were the most frequently used technology to support physical activity. Wearables are highly sensitive in detection of gait disturbances and fatigue in PwMS^{31, 32} and

evidence of their use to sustain physical activity behaviour is largely growing³³, thus they can be a valuable addition to walking programmes.

We noticed a mismatch between what PwMS were doing (in terms of physical activity) with what the research and clinical community made available during the pandemic. For example, a large number of video based resources were developed and widely circulated³⁴⁻³⁶, however only 3% of respondents in our sample used them during the pandemic. Similarly, usage of physiotherapy exercise platforms was minimal, highlighting the need to collaborate with PwMS during any future intervention developments to ensure the resources health care professionals provide are in line with the preferences of the end users. The LEAP-MS study is an example of good practice in public patient involvement in intervention and trial design³⁷.

Strengths and Limitations

Noteworthy are a few methodological considerations. The first is that data was collected within a multicentre setting in order to increase sample size. We noted that those countries using registers or MS societies were the ones who were the most successful in recruiting a bigger sample of patients, and thus we recommend future survey studies to consider this recruitment channel. We acknowledge the variation in number of respondents between countries as well as the high proportion of respondents from Norway. However, Supplementary Table 2 shows that the change in physical activity behaviour of the Norwegian respondents was not markedly different from that seen in the other countries, hence it is unlikely that the high proportion of Norwegian respondents has skewed the data of this international sample. Noteworthy, is that the survey was conducted during the pandemic (May – July 2021). We argue that additional factors other than the restrictions which aimed at reducing the spread of COVID-19 may have influenced physical activity behaviour. The

analysis of the association between stopping and reducing physical activity participation and factors such as disease severity, restrictions aimed at reducing the spread of COVID-19 and fear of contracting COVID-19 is explored within the project's working group, and will be reported elsewhere^{38,39}.

Conclusion

In PwMS, physical activity performance, especially at moderate and high intensities, decreased during the pandemic compared to pre-pandemic. PwMS who were active during the pandemic expressed the preference for delivery of physical activity in a hybrid form once the pandemic restrictions ended, while inactive PwMS preferred an in-person form of physical activity. The most frequent type of physical activity was walking. We propose a call for action to develop interventions that include walking programmes with specific emphasis on increasing physical activity. These interventions have an enormous potential to address the concerns of PwMS in terms of fear of contracting COVID-19 and are not reliant on a venue. Including wearable technologies as part of these interventions can be considered for PwMS who are keen to use them.

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List of Figures and tables.

Figure 1. Percentage distribution of age, years of diagnosis and patient determined disease steps scale across the responders.

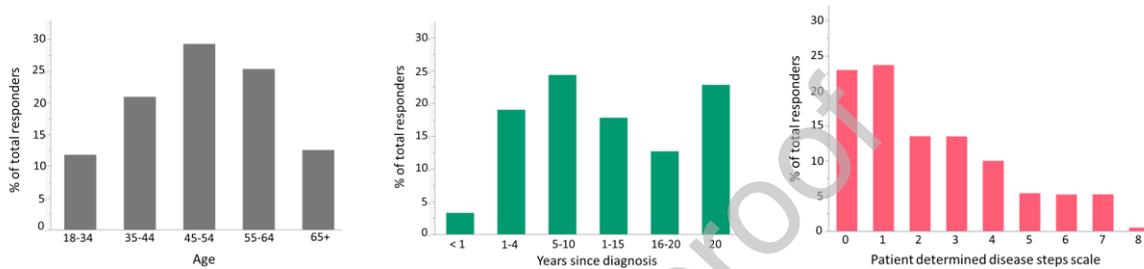


Figure 2. Percentage distribution of physical activity conducted pre- and during the pandemic.

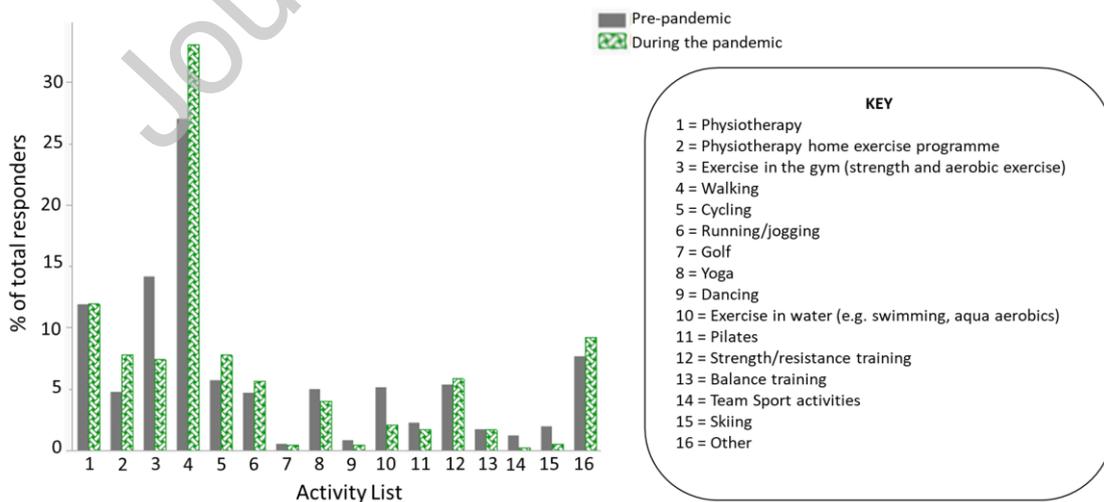


Table 1. Technology used to perform physical activity pre-pandemic and at survey completion by respondents who were physically active. Participants were instructed to select

	Pre-pandemic (%)	During the pandemic (%)
I did not use any technology	64	58
I used a wearable device – e.g. FitBit, smart watch, pedometer	21	24
I used an app on my phone, laptop or tablet	8	9
I used a live video call on my phone, laptop or tablet	1	2
I watched a recorded video on a device	2	3
I used a physiotherapy exercise website	0	1
I watched a live exercise class on the TV or device	7	1
Other	3	2

all answers that apply.

Table 2a. The perceived rating of the positive aspects of performing home based physical activity using technology. Participants were instructed to select all answers that apply.

	Proportion (%)
I can select when I do my physical activity (not dependent on class times, weather)	25
Not having to travel to the venue	16
Takes less time	11
Low cost	10
Enjoyment	7
There were no positive aspects	6
I learnt new skills to motivate me to exercise	6
Other	7

Table 2b. The perceived rating of the negative aspects of performing home based physical activity using technology. Participants were instructed to select all answers that apply.

	Proportion (%)
There were no negative aspects	29
Lack of social contact	16
Lack of social or in person contact (e.g. visual cues, eye contact, body language and visual feedback) that you get in a person	12
Difficult to find an appropriate space at home	11
Difficulty to do the exercises without physical support	8
I don't enjoy this type of physical activity	7
Other	8

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