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Original article

Underutilization of physical therapy for symptomatic women with MS during and following pregnancy



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ABSTRACT

Background: Many patients with MS continue to have symptoms of their disease even when inflammatory activity is reduced by DMTs. Although disease activity tends to be reduced during pregnancy – especially in the third trimester – women with MS can experience ongoing symptoms during pregnancy, or new ones in the immediate postpartum period, that degrade quality of life. While many MS-related and postpartum symptoms can be improved with physical therapy (PT), there are currently no guidelines on pregnancy-related rehabilitation in MS. In this analysis, we evaluated the prevalence of PT-amenable symptoms and patterns of PT referrals in a cohort of UCSF MS Clinic patients who became pregnant.

Methods: We extracted electronic medical records (EMR) data for the year before conception, during pregnancy, and year postpartum for women with MS cared for at UCSF between 09-2005 and 08-2019. This included clinical visits, MS therapies and symptoms (as defined by the National MS Society). PT and pelvic floor PT orders and notes were also extracted.

Results: We included 142 live birth pregnancies from 118 women. During the course of their pregnancy and within the year postpartum, 107 women (75.4%) reported at least one PT-amenable symptom. A total of 30 (28.0%) referrals were made to PT, with attendance confirmed for 10 (33.3% of referrals). Symptoms most commonly triggering a referral for PT evaluation were numbness and urinary incontinence. Falls were reported after 10 of the pregnancies; 4 resulted in a referral to PT. Forty-one women reported urinary incontinence: 11 (26.8%) were referred to PT, and 2 to pelvic floor PT. Nineteen women experienced a documented relapse during pregnancy and/or postpartum: 11 received a PT referral, and 4 attended PT.

Conclusions: While women with MS recorded at least 1 PT-amenable symptom during or following 75.4% of their pregnancies, only 28% of these were referred to PT – and only a third attended PT. Of significance was the 4.9% referral rate for pelvic floor PT in postpartum women with a record of urinary incontinence. Pelvic floor PT is a mainstay of general postpartum care in many European countries. These data illustrate critical gaps in rehabilitation referral, access and use at the intersection of neurological conditions and pregnancy in a large US-based MS clinic. They lend support for quality improvement efforts to improve care pathways and for telerehabilitation innovations to reduce barriers to access and improve synergistic care between PT, MD and urologic care.

1. Introduction

Multiple sclerosis (MS) affects a large number of women of child-bearing age. It is more common in women than men (3:1 female: male

sex ratio) and commonly has its first clinical manifestations in young adulthood. (Bove and Chitnis, 2013, Hauser et al., 2013) Pregnancy frequently represents a state of disease quiescence (particularly during the 3rd trimester), (Patras et al., 2013) although a rebound of disease

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activity has been described postpartum (or after cessation of the protective effects of breastfeeding). (Krysko et al., 2019) There is growing literature concerning how best to medically manage inflammatory activity before, during and after a pregnancy however there is little consensus on optimal rehabilitative approaches to help symptomatic women during this period.

MS symptoms occur as a result of inflammation, demyelination, and secondary nerve axonal damage. In the aggregate, these symptoms diminish independent movement and mobility as they can cause impairment of muscle function (i.e. weakness and spasticity); abnormal proprioception (i.e. numbness, paresthesia, diminished vibratory perception and pain); vertigo (i.e. dizziness and lightheadedness) and incontinence (bladder and bowel). (Gelfand, 2014, Akkoc et al., 2016) In addition, pregnancy itself can be associated with worsening of balance, gait, sensory disturbances and bladder function in the general population. (Gynecologists ACoOa 2020)

Many of these symptoms can be improved with physical therapy (PT), which is designed to improve and maintain optimal function by means of mechanical, manual, and educational interventions. People with MS (PwMS) who are symptomatic, or have underlying sequelae from previous relapses should be referred to PT for rehabilitation. (Thompson, 2001, Pereira et al., 2017, Motl et al., 2017, Khan et al., 2017) Some benefits of PT include lack of drug interactions with MS-disease modifying therapies, high level of tolerability, and few (or no) unwanted side effects. The American College of Obstetricians and Gynecologists (ACOG) recommends that pregnant women maintain an active lifestyle. (Gynecologists ACoOa 2020) For bladder function specifically, in the general population, as well as for people with neurodegenerative disease such as MS, pelvic floor PT (also known as women's health PT or pelvic health PT) has demonstrated benefits for alleviating bladder symptoms, improving function and enhancing quality of life. (Thompson, 2001, Block et al., 2015) In MS, pelvic floor PT should be used as a first line treatment for bladder symptoms. (Block et al., 2015)

Despite the potential benefits of PT in postpartum women with MS, there are currently no guidelines for this population in the US. In the current analysis, we evaluate the prevalence of PT-amenable clinical symptoms, as well as patterns of referrals to PT, in women with MS who underwent a pregnancy while cared for at the UCSF MS and Neuroinflammation Center. We hypothesized that many women who experience PT-amenable symptoms postpartum were not being referred to PT, or further, did not attend PT after a referral.

2. Methods

2.1. Sample selection

We performed a retrospective analysis of prospectively collected clinical data from women with MS cared for at the University of California, San Francisco (UCSF) Center for Multiple Sclerosis and Neuroinflammation. We screened the electronic medical record (EMR) to identify women who became pregnant between 2015 and 2019 and for whom prospectively recorded clinical data were available. A cohort of 118 women, with 151 pregnancies, was identified (during chart review, any additional pregnancies for these 118 women that preceded the search window were included between 2005 and 2015). Women participating in an ongoing prospective pregnancy registry that began in 2019 were excluded (N=56 as of July 15, 2020).

2.2. Data Collection

Data collected. Maternal demographics, pregnancy and delivery details, and MS clinical history were extracted from the EMR. MS course at conception, during pregnancy, and postpartum included clinical visits, MS therapies, MRI reports, and MS symptoms, as previously described, (Anderson et al., 2020) as well as orders placed.

2.2.1. Rehabilitation-associated symptoms

Clinical symptoms considered to be amenable to PT intervention were collected for 12 months before conception, pregnancy, and 12 months post-partum. These were categorized based on the descriptions provided by the National Multiple Sclerosis Society (National MS Society, 2013), as follows: a) Difficulty walking due to balance - any mention of imbalance problems affecting the patient's mobility; b) Diminished vibratory perception - any decrease in sensing vibration during a physical exam by a neurologist; c) Falls - any accident in which the patient lost their balance, slipped, or collapsed to touch the ground inadvertently; d) Numbness - any complaints by the patient of a lack of sensation; e) Pain - mostly in legs and/or feet - was defined by any complaint the patient had regarding physical pain anywhere below their hips; f) Paresthesia - any complaint by the patient of a tingling or pins-and-needles sensation; g) Spasticity - any complaint by the patient of stiffness, tightness, or spasms of the muscles; h) Bladder dysfunction - taken as any urinary issues reported by the patient; and i) Vertigo - a persistent complaint of dizziness by the patient.

2.2.2. Rehabilitation Care

Since all orders are electronically placed within our health system, we searched initially for any rehabilitation order in the EMR. The main types of PT order included: PT, Pelvic floor PT and Home PT (defined as any mention of exercises at home by a primary caretaker, neurologist, obstetrician, or PT). Referrals could have been placed by the MS clinician, obstetrician, or 'other' provider and been ordered either at the time of a clinical (in-person or via televideo) visit or any time thereafter within one year of delivery.

To further identify referral orders placed and PT encounters completed outside our health system, we also reviewed all clinical notes within our system for the year following delivery, all referral notes from external sources scanned to the patient's UCSF chart, as well as the rest of a patient's EMR through Care Everywhere, which provides access to medical records from other health systems.

If there was PT documented in the EMR, yet no specific PT order present, a PT order was assumed and included. Pelvic floor PT referral was made by the patients' neurologist and often by the obstetrician; both were included in the analysis.

Ethical approvals. The UCSF Committee of Human Research approved the study protocol for retrospective analysis of EMR-derived MS data with no patient contact (Ref #13-11686).

Statistical analysis. We conducted descriptive statistics to quantify the number and frequency of PT-amenable symptoms, as well as the frequency of referrals. Statistical analysis and graphical representation were generated using JMP Pro 15 and Microsoft excel version 16.37.

3. Results

3.1. Characteristics of the study cohort

There were 151 pregnancies, with 142 deliveries, from 118 women who conceived between September 2005 till August 2019; 9 pregnancies resulted in pregnancy loss. Among the 118 women contributing live-birth pregnancies, 88 women contributed 1 pregnancy (2 had twins), 18 women contributed 2 pregnancies, and 6 women contributed 3 pregnancies. (Table 1) Mode of delivery included normal spontaneous vaginal delivery (NSVD, n=67, 47.2%), induced vaginal delivery (n=10, 7.0%), forceps- or vacuum-assisted or both (n=7, 4.9%), or cesarean section (n=30, 21.1%); 28 deliveries had no delivery type recorded in the EMR.

3.2. Physical Therapy-Amenable Symptoms and Referrals

During the course of the pregnancy and within the year postpartum, in 107 pregnancies (75.4%) women had at least one PT-amenable symptom reported in the EMR (Figure 1). The most frequent recorded

Table 1
Demographic and clinical characteristics of 118 women contributing 142 deliveries, Demographic, Symptom Frequency in Pregnant and Postpartum Women with Multiple Sclerosis

Demographic (EMR review from 09/2005 –to 08/2019)	Total Cohort	Women Referred to PT	Women who attended PT
Sample Size	151/142 (pregnancies/ deliveries)	30/112 ** (referrals to PT/PT- amenable Sx)	10/ 30 (attended PT/ of those referred)
Total number of women with resulting live births (Women with 1/ 2/ or 3 pregnancies)	118 (88*/ 18/ 6)	-	-
Delivery Type – NSVD. N (%)	67 (47.1%)	18/30	5/10
Pregnancy relapse – N/ total (%)	19/142 (13.4)	11/30 (36.7)	4/9 (44.4)
Symptoms reported in clinical neurological notes (N, % pregnancies)	(N/142)	(N/30)	(N/10)
Falls	10	4	2
Balance issues	10	5	2
Pain	28	6	1
Incontinence	41	11	3
Vertigo	24	4	1
Numbness	67	17	7
Vibratory loss	40	6	2
Spasticity	20	6	3

Legend: Sx = Symptoms, PT = physical therapy, NSVD = normal spontaneous vaginal delivery.

* 2 women had twins

** 107 with PT amenable symptoms + 5 referred to PT for “Exercise PT”.

symptoms were: paresthesia (30%), urinary incontinence (29%), diminished vibratory perception (28%), pain in the lower extremities (20%) and vertigo (17%) (Figure 2, Table 2). We secondarily categorized urinary incontinence, pain in the lower extremities and vertigo as more amenable to PT than sensory changes, for which PT interventions may be less effective; at least 1 of these 3 symptoms were present in 66 pregnancies.

3.3. Symptom patterns referred to PT

Among these 107 pregnancies with PT-amenable symptoms, 25 (23.4%) referrals were made to PT; another 5 women did not have specific PT-amenable symptoms reported in the EMR but were referred

for “Exercise PT”. Among the 30 pregnancies with PT referrals that we were able to confirm from our review, 10 (33.3%) had a note in the EMR affirming attendance at PT (Table 1).

For the cohort as a whole (n=142), the mean number of PT-amenable symptoms documented for each woman was 1.80 (SD 1.66). For the women referred to PT, the mean number increased to 2.43 (SD 2.18) symptoms – and women who attended PT registered a mean of 3.10 (SD 2.23) symptoms.

Only a fraction of women were referred to PT for complaints of imbalance (40%; 6/15), numbness (21.5%; 17/79), spasticity in one or more of their limbs (17.4%, 4/23), pain in their legs and feet (17.9%, 7/ 39), paresthesia (14.3%, 6/42), vertigo (12.5%, 3/24), or for vibratory loss on examination (12.5%, 6/48).

Falls were reported after 10 of the pregnancies; only 4 resulted in a referral to PT.

With respect to urologic complaints, of the 41 women with reports of urinary incontinence, only 26.8% (11/41) were referred to PT and just 2 were referred specifically to pelvic floor PT. The PT treatment plan generally consisted of at least 6 weeks, and up to 3 months (mostly 8-12 sessions) of PT exercise.

Altogether, there was no documentation in the notes of women’s reasons for not attending PT when this had been recommended.

Nineteen women had documentation of a relapse in the EMR during their pregnancy, of these 9 suffered at least one more relapse within the year postpartum. Relapse manifestations included falls (n=4, 21.1%), numbness (n=13, 68.4%; mostly on the hands and face), urinary symptoms (n=11, 57.9%), pain (n=8, 42.1%), spasticity (n=7, 36.8%) and balance issues (n=5, 26.3 %). PT was ordered for 11 of the 19 (57.9%). There was a record of attendance in only 4 (2 received PT before pregnancy, 1 during, and 1 postpartum): for fall (n=1) and urinary incontinence (urgency and /or frequency, n=3; 1 of whom was specifically referred to pelvic floor PT).

4. Discussion

In this cohort of 118 completed pregnancies in women with MS cared for in a tertiary care center, a large percentage (75.4%) were observed to have at least one symptom where PT referral could and probably should be recommended; among these, only one third had documentation of a referral, of whom only 33.3% had record of attending at least one PT session. Of significance, was the lack of referral (4.9%) for pelvic floor PT in postpartum women who reported urinary incontinence.

During pregnancy, women undergo a number of physiological and musculoskeletal fluctuations over short periods of time. PT is considered safe for women with MS who are planning pregnancy, during pregnancy,

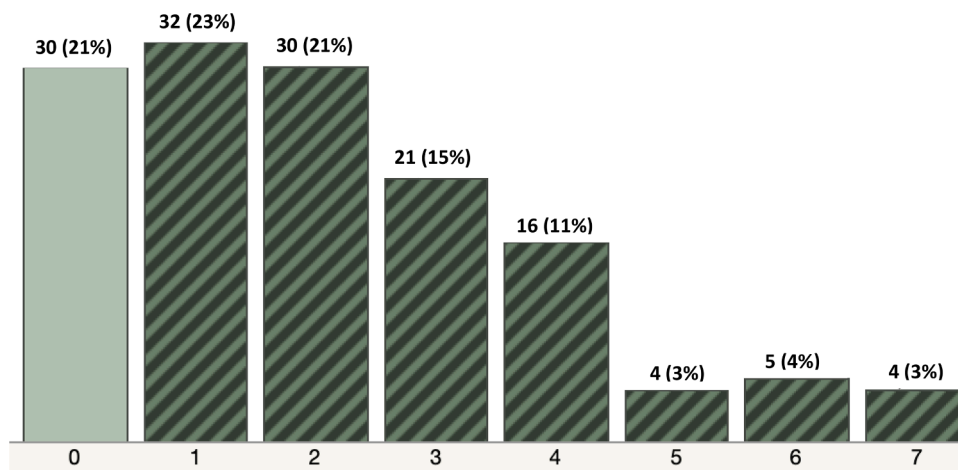


Figure 1. Number of PT Amenable Symptoms Reported by Women with Multiple Sclerosis During Pregnancy or Post-partum
Legend: Number and percentage of symptoms reported in the electronic medical records.

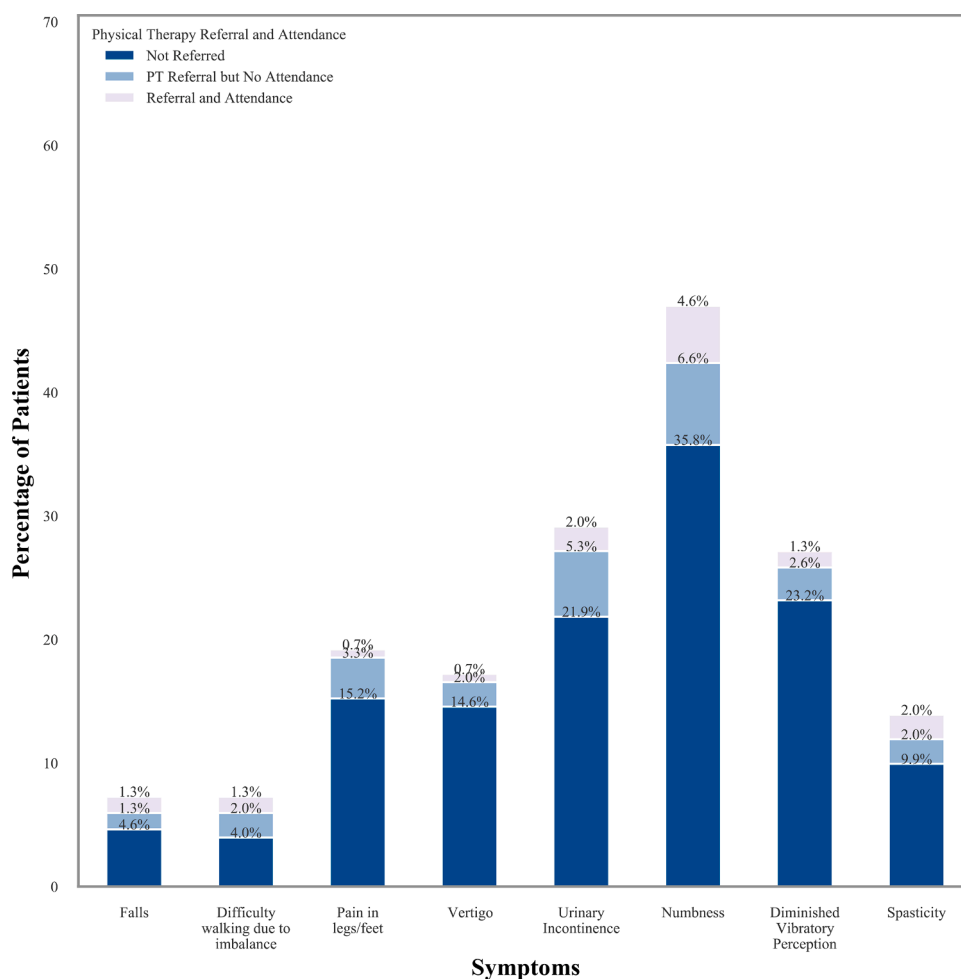


Figure 2. Patterns of Referral and Attendance to Physical Therapy in our Cohort

Legend: Physical therapy (PT) amenable symptoms reported by pregnant women with MS, depicted by percentage: not referred to PT, referred to PT but did not attend, and those that were referred and attended PT.

Table 2
Underutilization of Physical Therapy Resources for Symptomatic Women with MS During and Following Pregnancy

Physical Therapy Ordered	Physical Therapy Attended	Percentage of Patients Affected by Symptoms (Total: 151 Patients)							
		Falls	Imbalance	Pain	Vertigo	Urinary Incontinence	Numbness	Diminished Vibratory Perceptions	Spasticity
No	N/A	4.64	3.97	15.23	14.57	21.85	35.76	23.18	9.93
Yes	No	1.32	1.99	3.31	1.99	5.30	6.62	2.65	1.99
	Yes	1.32	1.32	0.66	0.66	1.99	4.64	1.32	1.99
SUM		7.28	7.28	19.20	17.22	29.14	47.02	27.15	13.91

and while still breastfeeding. (Bove et al., 2014) PT performed correctly does not affect the fetus, newborn or lactation, and can therefore be a safe option throughout pregnancy. In the general population, PT is used to relieve lower back pain, pelvic girdle pain and incontinence associated with pregnancy; (Physical activity guidelines for Americans 2018) postpartum, PT is also used to treat Diastasis Recti Abdominis. (Litoss, 2014)

With respect to urologic symptoms in many countries payors cover postpartum pelvic floor PT for all women (e.g. in France, government insurance guarantees women 10 to 20 sessions of ‘rééducation périnéale’ - pelvic re-education) in recognition of its postpartum prevalence. (Senat et al., 2016) This is not the case in the United States, despite the recommendations by the American College of Obstetricians and Gynecologists (ACOG) to seek therapy (PT) if incontinence issues are present. (Practice Bulletin No. 165 2016, Practice Bulletin No 2015)

Women with MS may experience MS-related symptoms in addition to other neurological sequelae of pregnancy (such as meralgia parasthetica, obstetrical-related urinary dysfunction, carpal tunnel syndrome, etc.), many of which are responsive to PT intervention. The advantages of PT might be even more prominently enhanced in the setting of postpartum relapses, which could influence a mother’s ability to care for their child, or themselves. However, and despite its benefits in the general population, literature on postpartum PT for women with MS is scant. Recommendations range from seeking healthcare provider advice for post-partum depression (no mention of specific rehabilitation), (National MS Society, 2013) to advocating for “supportive treatment and rehabilitation” throughout pregnancy.

In our cohort, the low rates of referral to PT could reflect not only clinicians’ lack of attention (‘blind spot’) to the focused rehabilitation needs of this patient population, but also a general lack of awareness

about the benefits of PT. Surprisingly also, only one third of the women who were referred to PT were documented to attend even a single session. Potential explanations for this are: 1) lack of education (both for clinicians and patients) on the use and benefits of women's health PT for incontinence as well as pregnancy related physical symptoms; 2) the overwhelming responsibilities of new motherhood and the challenge of leaving the house for a PT appointment especially when symptoms make moving autonomously hard or when the potential benefits are unclear; and /or 3) if sessions are not covered by insurance, there may be financial barriers to attending women's health PT, including access barriers to PTs skilled in MS care and inconveniences of current PT practice (delays in scheduling or availability of specialized PT). Additionally, although the Family and Medical Leave Act entitles women in the United States to 12 weeks of maternity leave (considerably shorter than other first-world countries), (Bryant, 2020) actual leave may differ due to variances in individual employer policies. This short period to adapt to motherhood, or increased childcare challenges, together with the fact that much of the leave is unpaid may also negatively affect PT attendance (if referred). (Van Niel et al., 2020)

Limitations of our study included its retrospective nature, the lack of systematic ascertainment of symptoms, referral rates and completed referrals which could have reduced our ability to capture PT sessions completed in clinics not sharing EMR data with UCSF (which would overestimate the problem: lack of PT referral and attendance). If patients attended PT outside of our system and the notes are not shared, (a limitation of our fragmented system) this would also overestimate the problem. Additionally, we lack qualitative understanding of reasons for non-referral by clinicians and non-participation by patients.

Neurorehabilitation should be done under the supervision of a specialist to avoid compensations (bad biomechanical habits or compensatory movement strategies) and learned non-use due to central sensitization to pain (pain hypersensitivity). (Cramer et al., 2011) Specialized PTs can prevent harmful compensations so as to reduce compounding already disabling symptoms, particularly during pregnancy and postpartum. (Cramer et al., 2011, Tomassini et al., 2012)

These data highlight a critical need for quality and systems improvement interventions to improve referral for evidence-based pregnancy and postpartum physical rehabilitation in patients with MS. For example, in Parkinson's disease researchers developed a quality indicator for physiotherapy interventions, finding the instrument to be relevant, reliable, discriminative and feasible to assess adherence to guidelines. (Nijkrake et al., 2009) These observations also illustrate the need for consensus recommendations and evidence-based guidelines for rehabilitation during and after pregnancy in patients with MS.

5. Conclusion

While women with MS recorded at least 1 PT-amenable symptom during or following 75.4% of their pregnancies, only 28% of these were referred to PT – and only a third attended PT. Of significance was the 4.9% referral rate for pelvic floor PT in postpartum women with a record of urinary incontinence. Pelvic floor PT is a mainstay of general postpartum care in many European countries. These data illustrate critical gaps in rehabilitation referral, access and use at the intersection of neurological conditions and pregnancy in a large US-based MS clinic. They lend support for quality improvement efforts to improve care pathways and for telerehabilitation innovations (leveraging advances in telehealth generally for MS) (Damotte et al., 2019, Bove et al., 2018) to reduce barriers to access and improve synergistic care between PT, MD and urologic care.

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CRedit authorship contribution statement

Valerie J Block: Conceptualization, Data curation, Formal analysis, Visualization, Writing - original draft. **Olivia Mestas:** Data curation, Formal analysis, Writing - review & editing. **Annika Anderson:** Data curation, Writing - review & editing. **Jessica Singh:** Visualization, Writing - review & editing. **Leah Wylie:** Validation, Writing - review & editing. **Chu-Yueh Guo:** Methodology, Writing - review & editing. **Ari J Green:** Methodology, Writing - review & editing. **Jeffrey M Gelfand:** Methodology, Writing - review & editing. **Riley Bove:** Conceptualization, Investigation, Methodology, Supervision, Validation, Writing - review & editing.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.msard.2020.102703](https://doi.org/10.1016/j.msard.2020.102703).

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