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Research in action

Clinical characteristics of COVID-19 infection in polyhandicapped persons in France

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Aim: Little is known about the clinical profile of COVID-19 infection in polyhandicapped persons. This study aimed to describe the characteristics of this infection among individuals with polyhandicap.

Method: This was a retrospective observational study. Polyhandicap was defined by the combination of motor deficiency, profound mental retardation, and age at onset of cerebral lesion younger than 6 years. A positive COVID-19 status was considered for patients with a positive COVID-19 laboratory test result, or patients presenting with compatible symptoms and living in an institution or at home with other patients or relatives who had laboratory-confirmed COVID-19 infection. Data collection included sociodemographic data, clinical and paraclinical characteristics, as well as the management and treatment for COVID-19 infection.

Results: We collected 98 cases, with a sex ratio of 0.98 and a mean age of 38.5 years (3 months to 73 years). COVID-19 infection was paucisymptomatic in 46% of patients, 20.6% of patients presented with dyspnea, while the most frequent extra-respiratory symptoms were digestive (26.5%) and neurological changes (24.5%); 18 patients required hospital admission, four adults died. The mean duration of infection was longer for adults than for children, and the proportion of taste and smell disorders was higher in older patients.

Conclusion: These findings suggest that PLH persons often develop paucisymptomatic forms of COVID-19 infection, although they may also experience severe outcomes, including death. Clinicians should be aware that COVID-19 symptoms in PLH persons are often extra-respiratory signs, mostly digestive and neurologic, which may help in the earlier identification of COVID-19 infection in this particular population of patients.

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Abbreviations: FIM, Functional Independence Measure; IQR, interquartile ranges; MD, missing data; PLH, polyhandicap; SD, standard deviation.
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1. Introduction

Polyhandicap (PHL), as a recently defined concept [1–3], is a serious health condition with severe and complex disabilities corresponding to a chronic disorder occurring in an immature brain, which leads to a combination of profound intellectual disability and serious motor disorder and results in an extreme restriction of autonomy and communication. These neurological, intellectual, and motor disabilities are frequently accompanied by sensory deficits and behavioral and relational disorders. This term is similar to the notion of “profound intellectual and multiple disabilities,” which is used in other countries but does not systematically refer to a disorder affecting an immature brain [4]. The prevalence of polyhandicap in France is estimated to be between 0.7 and 1.28 per thousand, i.e., 880 new cases of children with polyhandicap per year [5–7]. Persons with PHL have numerous comorbidities, and the main cause of death among these patients is respiratory failure after recurrent pulmonary infections resulting from a combination of different factors (including scoliosis with thoracic deformation, swallowing disorders, gastroesophageal reflux disease, insufficient bronchial drainage measures, and transit disorders, etc.) [8–12]. Since the beginning of the COVID-19 pandemic, a variety of manifestations have been reported both in adults and children, and a greater frequency of complications and death from COVID-19 infection has been widely documented in patients with chronic pathologies and comorbidities as well as in people over 70 years of age [13]. It is therefore reasonable to study the consequences of COVID-19 infection in polyhandicapped patients. This issue led a group of physicians in France specializing in polyhandicap to conduct an observational study on COVID-19 infection in this population of patients so as to identify the specific characteristics of the infection among patients with polyhandicap (respiratory and extra-respiratory symptoms) and the occurrence of complications (severe forms) and death. These findings will help medical teams perform a prompt diagnosis of this infection and optimize their care management and hospital discharge as most of these patients live in nonmedicalized institutions and sometimes at their parents’ homes. The aim of this study was to describe:

- the clinical profile of the COVID-19 infection;
- the occurrence of complications and death in this fragile population of patients.

2. Method and participants

Data were collected retrospectively through a questionnaire form that was sent to practitioners working in specialized institutions and rehabilitation centers for PHL persons and to practitioners of pediatric/neurologic university hospitals. Practitioners retrieved information from the patient files and answered the questionnaire with the information they obtained.

2.1. Selection criteria

We chose to target people with polyhandicap defined by the combination of motor deficiency (quadriplegia, hemiparesis as a predominant hemibody motor impairment, diplegia, extra-pyramidal syndrome, cerebellar syndrome, and/or neuromuscular problems) and severe/profound mental impairment (intelligence quotient < 40); for patients older than 5 years: IQ= developmental age below 2 years old; for children 3–5 years old: IQ= developmental quotient < 40% or not assessable) associated with everyday life dependence (Functional Independence Measure < 55) and restricted mobility (Gross Motor Function Scale [GMFCS and GMFCS-ER], III, IV and V [14]) with age at onset of cerebral lesion below 6 years.

COVID-19-positive status was accepted if the patient had a positive COVID-19 laboratory test result (reverse-transcriptase polymerase chain reaction [RT-PCR]), if the patient had compatible symptoms for COVID-19 care and lived in an institution where at least two patients had COVID-19 infection confirmed by laboratory tests, or if a patient with compatible symptoms for COVID-19 lived with relatives (parents, siblings) who had a diagnosis of laboratory-confirmed COVID-19 infection (in accordance with the French Health Policy recommendations).

The parents and/or legal representative received written information on this observational study, and their non-opposition to the use of their child’s health data was collected. This study followed the STROBE guidelines.

2.2. Data collection

The following patient characteristics at baseline were collected:

- Sociodemographic data: gender, age, type of care (specialized rehabilitation centers, residential facility, or home care), and geographic area;
- Etiologies for polyhandicap: unknown etiology; known etiology: constitutional or acquired;
- Main comorbidities: epilepsy (yes/no), swallowing disorders (yes/no), orthopedic (scoliosis with thoracic deformation), pulmonary (recurrent pulmonary infections: up to 3/year, patient receiving respiratory treatments [aerosols, beta-2 mimetics]) and digestive (gastroesophageal reflux disease and the need for enteral nutrition);
- COVID-19 infection diagnosis: laboratory test (RT-PCR, institutionalized patient, and home cluster).

Clinical features of COVID-19 infection in polyhandicapped patients: general symptoms such as occurrence of fever and mean fever degree as well as increased swallowing disorders; respiratory symptoms: dyspnea, hypoxia, findings of pulmonary auscultation (lung consolidation, diffuse bronchial congestion); extra-respiratory signs: neurological symptoms (modification of consciousness or behavioral modifications), epileptic seizure or increased frequency of epileptic seizures in epileptic patients, when evaluable, difficulty with sense of smell or taste; digestive symptoms (diarrhea, vomiting) and cutaneous disorders appearing during the COVID-19 infection. Paucisymptomatic presentation of COVID-19 infection was defined as patients presenting only mild symptoms (slight elevation of temperature (< 38.5°C), tympanic inflammation, throat redness, nasal congestion) without respiratory symptoms.

The paraclinical features (imaging and blood tests) of COVID-19 infection in polyhandicapped patients: findings on chest X-rays (lobe consolidation, diffuse bronchial infiltration). Occurrence of ground-glass opacities on chest computerized tomography (CCT) [15]. Abnormal blood test results (lymphocytopenia, neutropenia) and higher C-reactive protein (CRP) levels were observed during COVID-19 infection.

Therapies and care management of COVID-19 infection: main treatment prescribed (antibiotic treatment, hydroxychloroquine, oxygen therapy) and the need for noninvasive mechanical ventilation. Care management: transfer to a medicalized structure (hospital discharge, admission to an intensive care unit [effective or required but declined]).

Patient outcome after COVID-19 infection: death or deterioration of health status defined by weight loss. Comparisons were made between patients under and over 50 years of age since in the
general population people aged over 50 are considered at higher risk of a severe outcome after COVID-19 infection (https://www.has-sante.fr/jcms/p_3240076/fr/covid-19-quels-levierv-pour-vacciner-plus-vite-les-personnes-les-plus-vulnérables).

2.3. Ethics

Regulatory monitoring was performed according to the French law that requires the approval of the French ethics committee (Comité d'éthique de la recherche de la Société Française de Pédiatrie: CERSFP_2020_118). This study was registered on the AP-HM anonymous health data portal, PADS20-108.

2.4. Statistical analysis

Statistical analyses were performed using SPSS software (IBM SPSS PASW Statistics Inc., Chicago, IL, USA). Qualitative variables are presented as number and proportion for the two groups. Quantitative variables are presented as mean, standard deviation, median, and 25th and 75th percentiles. Depending on the distribution of the variables, chi-squared or Fisher’s exact tests were used for qualitative variables. Comparisons between the two groups were made with the usual tests (Student’s t test, ANOVA) and nonparametric tests (Mann–Whitney, Kruskal–Wallis) according to the applicability of these different tests.

3. Results

3.1. General characteristics of the patients

Between April 1, 2020 and July 1, 2020, we collected a total of 98 questionnaire forms from patients who met the COVID-19 criteria. The first cases of COVID-19 occurred in March 2020, and the last cases occurred in June 2020. The diagnosis of COVID-19 infection was based on:

- laboratory tests for 79.6% of the patients;
- cluster of institutionalized patients as defined previously for 17.3% of the patients;
- home cluster for 3.1% of the patients.

3.1.1. Etiologies

Etiologies of polyhandicap were unknown for 30.6% of the cases. Among the known etiologies, 48.4% (n = 33) were constitutional: 4.4% (n = 3) of the patients presented with central nervous system malformations, 35.2% (n = 24) of the patients presented with neurometabolic or neurogenetic diseases, 8.8% (n = 6) of the patients presented with epileptic encephalopathy, and 51.6% (n = 35) presented with an acquired disease (see Table 1 for details).

3.1.2. Main comorbidities

The frequency of associated comorbidities in decreasing order was as follows: epilepsy 56.1% (n = 55), swallowing disorders 40.8% (n = 40), scoliosis 16.3% (n = 16), gastroesophageal reflux 13.4% (n = 13), and recurrent pulmonary infections 6.1% (n = 6). Overall, 12.2% (n = 12) received enteral nutrition and 5.1% (n = 5) received baseline respiratory treatments (see Table 1 for details).

3.1.3. Health characteristics of COVID-19 infection

COVID-19 infection was paucisymptomatic in 46% of the patients (n = 45), and all of them had a positive PCR result. Fever was the most constant symptom (68.4%; n = 67). The most frequent respiratory symptoms were dyspnea (20.6%, n = 20), hypoxemia (28.9%, n = 28), and bronchial congestion (21.6%, n = 21). The most frequent extra-respiratory symptoms were digestive symptoms (diarrhea/vomiting) 26.5% (n = 26), followed by neurological symptoms, modification of consciousness and/or behavior 24.5% (n = 24), difficulty with taste and smell 11.8% (n = 10), and increased epileptic seizures or epileptic seizures appearing in nonepileptic patients, 1% (n = 3). See Table 2 for details.

3.1.4. Paraclinical features

Only 9.8% (n = 8) of the patients had a chest X-ray (the main radiologic abnormalities were lobe consolidation or diffuse infiltration), and only 12.5% (n = 10) of the patients had CCT, showing specific COVID-19 changes in all cases. The main laboratory abnormalities were, in decreasing order, elevated C-reactive protein (CRP) levels, lymphopenia and neutropenia (see Table 2 for details).

3.1.5. Treatment and care management for COVID-19 infection

The main treatment modalities for COVID-19 infection were antibiotic treatments in 36 patients (37.1% of cases), and the most frequently used antibiotic was azithromycin; one third of the patients received oxygen therapy, and only two patients needed noninvasive mechanical ventilation.

Overall, 18 patients (18.3%) required hospital admission, five needed intensive care unit (ICU) admission (one of them was not admitted to the ICU), and four patients died. All deceased patients were adults, with an age range of 21–63 years. Three of these patients were men, none were prone to episodes of recurrent pulmonary infections, one had scoliosis, and two had swallowing disorders. All deceased patients presented with respiratory symptoms, and two of them had an altered state of consciousness.

| Table 1 |
| --- |
| Sociodemographics and health status of polyhandicapped persons (N=98). |
|  |
| Sociodemographics | N (%) | MD % |
| --- | --- | --- |
| Sex ratio | Men/women | 0.98 | 3 (3.1) |
| Age | Mean ± SD | 38.5 ± 18.3 | 0 (0) |
| Children/adults | 18/80 | 0 (0) |
| Care modality/structure | Spec. re-educ. center | 20 (20.5) | 12 (12.2) |
| | Residential facility | 57 (58.1) |
| | Home care | 9 (9.4) |
| Geographical area | Ile-de-France | 49 (50) | 0 (0) |
| | Hauts-de-France | 24 (24.5) |
| | Provence-Alpes-Côte d'Azur | 23 (23.5) |
| | Bourgogne-Franche-Comté | 1 (1) |
| | Normandie | 1 (1) |
| Etiology | Unknown | 30 (30.6) | 0 (0) |
| | Constitutional | 33 (33.7) |
| | Pre-perinatal | 21 (21.4) |
| | Postnatal | 14 (14.3) |
| Comorbidities | Epilepsy | Presence of epilepsy | 55 (56.1) | 0 (0) |
| | Swallowing disorders | | 40 (40.8) | 0 (0) |
| | Orthopedic | Scoliosis | 16 (16.3) | 0 (0) |
| | | Pulmonary | Recurrent pulm. infections | 6 (6.1) | 0 (0) |
| | | | Respiratory treatments | 5 (5.1) | 0 (0) |
| | Digestive | Gastroesophageal reflux | 13 (13.4) | 0 (0) |
| | | Enteral nutrition | 12 (12.2) | 0 (0) |
| Diagnosis of COVID-19 infection | RT-PCR | 78 (79.6) | 0 (0) |
| | Institution infection \( ^{a} \) | 17 (17.3) |
| | Familial infection \( ^{b} \) | 3 (3.1) |

MD: Mean deviation; RT-PCR: reverse transcriptase-polymerase chain reaction.  
\( ^{a} \) Patient with compatible symptoms for COVID-19 cared for in an institution where at least two patients had a COVID-19 infection confirmed by a laboratory test.  
\( ^{b} \) Patient with compatible symptoms for COVID-19 living with relatives (parents, siblings) having a diagnosis of laboratory-confirmed COVID-19 infection.
After the onset of COVID-19 infection, one third of the patients experienced weight loss (see Table 2 for details).

3.2. Comparison between boys/men and girls/women

There was no significant difference in patient gender in terms of general health characteristics, comorbidities, therapies and care management, and patient outcomes. COVID-19 symptoms did not differ by gender except for digestive troubles, which were significantly more frequent in girls than in boys (see Table 3 for details).

3.3. Comparison between adults and children and between older (over 50 years) and younger (under 50 years) patients

There was no significant difference between children and adults and between older and younger patients for general health characteristics, comorbidities, COVID-19 symptoms, therapies, and care management. The mean duration of COVID-19 infection was significantly longer for adults than for children, and the proportion of taste and smell disorders was significantly higher in older (over 50 years old) than in younger patients (see Tables 4 and 5 for details).

4. Discussion

Despite the increasing number of COVID-19 infections in the general population, little is known about the clinical profile of the disease in people with PLH. However, PLH persons are a vulnerable population who are potentially susceptible to adverse coronavirus 19 infection (COVID-19) outcomes as a consequence of their underlying severe chronic health condition. The proportion of patients with an unknown etiology for the polyhandicap (30%) was similar to the proportion reported in previous studies, which ranged from 15 to 60% [2]. Our population of patients had a high prevalence of specific comorbidities, such as epilepsy as well as scoliosis with thoracic deformation and swallowing disorders inducing respiratory problems, which are identified as risk factors for poor outcomes of COVID-19 infections [16]. Not surprisingly, the patients came from the French geographic areas most affected by the epidemic (northern and central and south-eastern), and most patients were cluster cases in institutional settings.

The first interesting finding is that the course of the disease was mild in 46% of PLH persons. This fact is surprising and unexpected in this fragile population with deteriorated health conditions and numerous associated comorbidities. Despite the nationwide character of this study, we report a limited number of pediatric
cases, which is consistent with published data reporting that children are less likely to be symptomatic or to develop severe symptoms compared with adults [17]. The main symptom of COVID-19 infection in PLH patients was fever (almost 70% of cases), and a quarter of the patients presented with respiratory symptoms. A quarter of the patients presented with extra-respiratory symptoms (digestive [diarrhea, vomiting] and neurologic [altered state of consciousness or behavioral modifications, and epilepsy]), whereas cutaneous disorders were found in only 5% of the patients. We observed some similarities between COVID-19 clinical features in PLH and older patients such as paucisymptomatic expression and digestive symptoms [18]. The low proportion of smell and taste disorders (12%) may be explained by under/misdiagnosis, which was due to the very low communication ability of the patients, making their evaluation challenging.

We did not find any gender difference for the severe forms of COVID-19 infection in PLH patients. These results differ from results reported for the general population, which usually show a higher proportion of severe forms in men [19]. The only difference observed for COVID-19 symptoms between the genders was an unexplained higher proportion of digestive symptoms in women (35.4%).

Table 3
Comparison between genders for health characteristics, COVID-19 symptoms, and outcomes.

| Patient characteristics | Girls/women N= 48, N (%) | Boys/men N= 47, N (%) | P |
|-------------------------|--------------------------|-----------------------|---|
| General characteristics |                          |                       |   |
| Children                | 6 (12.5)                 | 11 (23.4)             | 0.1 |
| Adults                  | 42 (87.5)                | 36 (76.6)             |   |
| Unknown etiology        | 37 (77.1)                | 30 (63.8)             | 0.1 |
| Comorbidities at baseline |                        |                       |   |
| Epilepsy                | 25 (52.1)                | 30 (63.8)             | 0.2 |
| Scoliosis               | 7 (14.6)                 | 7 (14.6)              | 1  |
| Recurrent pulmonary infections | 1 (2.1)    | 5 (10.6)              | 0.1 |
| Swallowing disorders    | 20 (41.7)                | 18 (38.3)             | 0.7 |
| Gastroesophageal reflux | 8 (16.7)                 | 5 (11)                | 0.4 |
| Enteral nutrition       | 3 (6.3)                  | 8 (17)                | 0.1 |
| COVID symptoms          |                          |                       |   |
| Pauci-symptomatic forms | 20 (41.7)                | 24 (51.5)             | 0.3 |
| Respiratory symptoms\*  | 16 (33.3)                | 15 (32)               | 0.8 |
| Altered state of consciousness | 15 (31.3) | 7 (15)                | 0.06 |
| Digestive symptoms      | 17 (35.4)                | 8 (17)                | 0.04 |
| Taste/smell difficulty  | 6 (14.3)                 | 4 (9.5)               | 0.5 |
| Treatments and care management for COVID-19 infection | | | |
| Hospital admission      | 8 (16.7)                 | 6 (12.8)              | 0.6 |
| Intensive care unit admission required | 2 (5.7) | 3 (8) | 1 |
| Patient outcome         |                          |                       |   |
| Weight loss             | 18 (37.5)                | 13 (29.5)             | 0.4 |
| Death                   | 1                       | 3                     |   |
| Duration of COVID-19 infection onset, M ± SD | 12.2 ± 9.3 | 9.2 ± 7.2 | 0.1 |

\* Dyspnea, hypoxia, lung consolidation, bronchial congestion.

Table 4
Comparison between adults and children for health characteristics, COVID-19 symptoms, and outcomes.

| Patient characteristics | Children N= 18, N (%) | Adults N= 80, N (%) | P |
|-------------------------|-----------------------|---------------------|---|
| General characteristics |                       |                     |   |
| Gender                  |                       |                     | 0.2 |
| Boys/men                | 11 (64.7)             | 36 (46.2)           |   |
| Girls/women             | 6 (35.3)              | 42 (53.8)           |   |
| Unknown etiology        | 4 (22.2)              | 26 (32.5)           | 0.4 |
| Comorbidities at baseline |                   |                     |   |
| Epilepsy                | 9 (50)                | 46 (57.5)           | 0.5 |
| Scoliosis               | 5 (27.8)              | 11 (13.8)           | 0.1 |
| Recurrent pulmonary infections | 2 (11.1)  | 4 (5)            | 0.5 |
| Swallowing disorders    | 9 (50)                | 3 (38.8)            | 0.3 |
| Gastroesophageal reflux | 4 (22.2)              | 8 (10)              | 0.1 |
| Enteral nutrition       | 3 (16.7)              | 10 (12.7)           | 0.7 |
| COVID symptoms          |                       |                     |   |
| Pauci-symptomatic forms | 11 (61)               | 34 (42.5)           | 0.1 |
| Respiratory symptoms\*  | 5 (29.4)              | 28 (35)             | 0.7 |
| Altered state of consciousness | 4 (22.2) | 20 (25)        | 1  |
| Digestive symptoms      | 5 (27.8)              | 21 (26.3)           | 1  |
| Taste/smell difficulty  | 0 (0)                 | 10 (13.7)           | 0.3 |
| Treatments and care management for COVID-19 infection | | | |
| Hospital admission      | 2 (11.1)              | 14 (17.5)           | 0.7 |
| Intensive care unit admission required | 2 (11.1) | 3 (5.3) | 0.5 |
| Patient outcome         |                       |                     |   |
| Weight loss             | 3 (17.6)              | 29 (37.2)           | 0.1 |
| Death                   | 0                     | 4                    |   |
| Duration of COVID-19 infection, M ± SD | 6 ± 7.5  | 12 ± 8.4 | 0.02 |

\* Dyspnea, hypoxia, lung consolidation, bronchial congestion.
We did not observe any differences in the clinical characteristics of COVID-19 infection across children and adults or between younger and older patients, except for a higher proportion of taste and smell disorders in older patients and a longer duration of COVID-19 infection in adults compared with children, which is consistent with the findings of previous studies reporting that children often have COVID-19 infection with low-to-moderate symptoms [17]. Although aging is associated with severe forms of COVID-19 infection, we did not find any difference between younger/children and older/adult patients for the severe symptoms of COVID-19 infection. However, all fatal cases in our study were adults; but the mean young age of our patients (38 years) may partly explain the relatively “low frequency” of fatalities in this fragile population of patients. Another explanation may be that older PLH patients do not have exposure to certain cardiovascular and cancer risk factors (tobacco and alcohol) and have a very low incidence of chronic diseases such as cancer, diabetes, and cardiovascular diseases [20]. Previous studies have found that people with intellectual disability had poorer COVID-19 outcomes [21]; in fact, our results reveal that nearly 20% of patients needed hospital admission for respiratory symptoms corresponding to severe forms of COVID-19 infections, and 5% developed critical disease with resuscitation offered. Four patients in our study died of COVID-19 infection, all of whom were adults; surprisingly, they did not present with pulmonary comorbidities at baseline. The case fatality rate of COVID-19 infection among PLH persons in our study was lower (4%) than the death rate among people with intellectual or developmental disability, varying from 5% in the United States (New York State) to 13% in the Netherlands [19]. However, COVID-19 infection had an impact on patient outcome, with a median duration of COVID-19 infection of 9 days, and a significant proportion of patients (40%) presented with weight loss after the infection.

A rather high proportion (37%) of patients received antibiotic treatments; this finding may be explained by the intention of the clinician to prevent bacterial super-infection and subsequent aggravation in these fragile patients. The study was not designed to investigate the modalities of virus transmission or the prevalence of infection in this population. Contrary to what was observed in institutions for dependent older people, we did not observe significant clusters of infection in institutionalized PLH patients. A specific study of the transmission of the virus to people with PLH would be useful.

This study shows that PLH patients are vulnerable to COVID-19 infection and should therefore be considered at high risk of severe forms of COVID-19, and appropriate measures should continue to be taken to protect them. The low mortality of COVID-19 infection in our population of PLH patients suggests that hospital care management is useful in these patients with severe forms. This outcome does not exclude the question of the level of management adapted to each patient on a case-by-case basis. As previously demonstrated for children with physical disabilities, it is important to maintain the medical care and rehabilitation adapted to the complex needs of PLH persons during this health crisis in order to prevent increased health deterioration [22].

The present study has several limitations. First, our analysis was based on a retrospective study, which might lead to bias and limit the generalizability and reliability of our results. Second, our results do not represent the general population of PLH patients but instead represent mostly patients cared for in institutions, as we could not make contact with all practitioners specializing in polyhandicap in France.

5. Conclusion

The findings of this study suggest that PLH persons often develop paucisymptomatic forms of COVID-19 infection, although they may also have severe outcomes, including death. Clinicians should be aware that the presenting symptoms of COVID-19 in PLH persons are often extra-respiratory signs, mostly digestive and neurologic, which may help in the earlier identification of COVID-19 infection in this particular population of patients.

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Disclosure of interest

The authors declare that they have no competing interest.

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