

Fear, changes in routine and dental care for children and adolescents with autism spectrum disorder in the COVID-19 pandemic: A survey with Brazilian parents

Bárbara Azevedo Machado¹ | Juliana Silva Moro¹  | Carla Massignam² |
Mariane Cardoso¹ | Michele Bolan¹

¹ Department of Dentistry, Federal University of Santa Catarina - UFSC, Florianópolis, SC, Brazil

² Department of Dentistry, University of Brasilia, Brasilia, DF, Brazil

Correspondence

Michele Bolan, Department of Dentistry, Federal University of Santa Catarina - UFSC, Delfino Conti Street, Trindade, Florianópolis, SC 88040-370, Brazil.
Email: michelebolan@hotmail.com

Abstract

Aims: This study aimed to report the perception of parents of children/adolescents with autism regarding the parents' fear of the pandemic by COVID-19. Also, to report children's fear about the use of individual protective equipment (IPE) in dental appointments, and the impact on the daily routine during the pandemic.

Methods and Results: A cross-sectional study through an open online survey was addressed to parents of children/adolescents autistic, aged between 3 and 18 years. The questionnaire had questions regarding the parents' fear of the COVID-19 pandemic, the parents' perception about the children/adolescents' fear of the use of IPEs at dental care, and the impact of the daily routine during the pandemic and social impact after the pandemic. Parents' reports on the degree of ASD (mild, moderate, and severe) of the child/adolescent. A total of 1001 responses were obtained. 50.35% of parents had high fear of the pandemic by COVID-19, 59.34% believe that children/teenagers will be afraid of the dentist's IPE and 61.64% responded that the COVID-19 pandemic had a high impact on the daily routine of children/adolescents with ASD.

Conclusions: Most parents reported fear of the pandemic by COVID-19, that children/adolescents with autism may be afraid of IPE and had a high impact on their daily routine during the pandemic.

KEYWORDS

autism spectrum disorder, COVID-19, dental care for children, oral hygiene

1 | INTRODUCTION

In December 2019, a new coronavirus, called Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) of unknown origin, spread in Hubei province, China and

affected more than 200 countries around the world. In March 2020, a pandemic was declared by the World Health Organization and in a short period of time, strict public health measures were applied all over the world, from social distance to home confinement in an attempt

to prevent the spread of coronavirus 19, also called COVID-19.^{1,2}

One of the consequences of the change in routine caused by the COVID-19 pandemic was closed schools, changing the daily routine of children and adolescents. These measures can result in an immediate and prolonged psychosocial impact, since schools play a central role in education, health and social life of children and adolescents.^{3,4} In this sense, this change in routine can be a potential stressor for children diagnosed with Autistic Spectrum Disorder (ASD) and their parents, especially for the most striking characteristics of this disorder, such as repetitive behavior and attachment to routine.^{5,6}

Besides the change in the daily routine of children and adolescents, the pandemic by COVID-19 has doubled the biosecurity care in dentistry, because dentist surgeons are the workers with the highest risk of exposure to the disease.⁷ In view of this, the protocol for the use of individual protective equipment (IPE) has undergone changes, requiring, for example, the use of face shields, N95 breathing filter masks, overcoats, in order to avoid or reduce contact by aerosols generated during dental procedures.⁸

Despite the pandemic, it is important that dental care, whether treatment or preventive, is maintained for children, including children and adolescents with ASD. The dental needs remained, however, the sudden change in the biosecurity measures adopted in the dental clinic due to the pandemic. Sensory disturbances that the dental environment can trigger by different stimuli⁹ including the use of IPE,⁸ due to “white coat hypertension” pathology,¹⁰ are factors that may cause or difficulties in a reduction in the acceptance of treatment by the autistic. Also, children/adolescents with ASD may present behavioral variations according to the degree of severity of the disorder.¹¹ Therefore, this study aimed to assess the parents of children/adolescents with ASD fear about the pandemic by COVID-19. This study was also aimed to report the parents’ perceptions of the children’s possible fear about IPE in the dental appointment and the impact on the daily routine of the children/adolescents during the COVID-19 pandemic.

In the present study, we raised three hypotheses: (I) Parents of children/adolescents with autism are highly fear of the COVID-19 pandemic; (II) Children/adolescents with ASD may be highly afraid of the use of IPE from the dentist after the change in protocols by COVID-19. (III) Children/adolescents with ASD had a high impact on their daily routine during the COVID-19 pandemic.

2 | METHODS

A cross-sectional study was carried out in September 1 to 16, 2020, through an anonymous online open survey

(*Google forms*) with 11 questions, aimed at parents or caregivers of children, aged between 3 and 18 years, diagnosed with ASD who were born or live in Brazil. At this time, the Brazilian population was under quarantine with a partial restriction on people circulation and all schools were closed. In Brazil, the number of children and adolescents with autism is unknown, since until the last census carried out in 2010, these data were not included in the survey. The next demographic census, approved by Law 13.861/19, will require the inclusion of this information. So far, no study with a sufficient sample has been conducted to demonstrate the prevalence of ASD. The study was approved by the Research Ethics Committee for Human Beings of the Federal University of Santa Catarina (UFSC-CEPSH) 4238285 and, is reported according to the CHERIES checklists (Eysenbach 2004).

The present survey used a convenience sample. For the size calculation, because the prevalence of fear of children/adolescents with ASD of IPE is unknown, we used a value of 50% prevalence, considering a significance level of 95% and an estimated 4% error. Performing the calculation, a value of 601 individuals was obtained. A correction factor of 1.2 was applied to compensate for the effect of the sample value, totaling 721 participants in the present study. To compensate for eventual losses, 30% was added to the calculation, making a total of 1029 individuals.

For the recruitment of participants, invitations were sent in several closed groups related to Autism Spectrum Disorder on the social networks “Facebook” and “Instagram”. An Instagram professional account was created (@autismoodonto) with a website link to the questionnaire in its biopage. In addition, other strategies were carried out, such as: sending the text to national, state and municipal associations and official pages on autism on social networks and via *Whatsapp* to disseminate the invitation to participate in the research. To minimize the chance of a single user filling out the same questionnaire multiple times, we checked the registration from the respondent’s email, and if it was duplicated, we would delete it. None incentive was offered to the participants to answer the survey.

Prior to the research, a pilot study was conducted with parents of children with ASD, representing 10% of the sample, in order to obtain information about the reliability and validity of the instrument. It was sent through the Association of Parents and Friends of Autistic People in Florianópolis. The difficulties found in understanding the questions, the adequacy or not in the order of presentation, and the number of questions were verified through the pilot research. After verification, there was no need to change the questions asked. The responses of the pilot study were not included in the present study. The Cronbach’s alpha analysis was performed for internal consistency

evaluation, obtaining a value of 0.73 (acceptable). No modification of the questionnaire was carried out after the pilot study.

By clicking on the link of the invitation to participate in the research, the participant was directed to a page containing the Informed Consent Form (ICF), clarifying the purpose of the study, its importance, the estimated time to respond to it, and information about the researchers responsible for the study. All participants included in the present study signed the ICF. Incomplete data were excluded, as were parents of children/adolescents with ASD who were not aged between 3 and 18 years.

The questionnaire directed to parents or caregivers asked about the child/adolescent ASD degree diagnosed by a medical professional in mild, moderate, and severe (later dichotomized into mild and moderate/severe).¹² In addition to this, seven multiple choice questions were included regarding the parents' fear of the COVID-19 pandemic, the parents' perception about the children/adolescents' fear of the use of IPEs at dental care, and the impact of the daily routine during and after the pandemic. To maximize participation, the questionnaire was designed to be short and only have closed questions.

The questions related to the perception of the responsible regarding pandemic COVID-19 (questions 1–4) were adapted from the “*Fear of COVID 19 Scale*” questionnaire by Ahorsu et al.¹³, translated into Portuguese by Faro et al.¹⁴ The possible answers were obtained on the *Likert Scale*, from one (strongly disagree) to five (Totally agree), being later dichotomized into “high fear” and “low fear” according to the mean of the total points (range 4–20 points). The higher the score, the greater the level of perceived fear.¹⁴ Question five refers to the parents' perception of the child's fear of the dentist use of IPE during the pandemic. The evaluation was based on a picture with the dental staff garmented with face shields, N95 breathing filter masks, overcoats, gloves and cap in the dental office. Question six refers to the fear and anxiety of parents if they needed to take the child for dental care during the pandemic. Questions seven and eight are related to the impact of routine child/adolescent with ASD during and after the pandemic, adapted from the study by Tull et al.¹⁵ The questions (7–8) were answered on a Likert scale of 1 to 5 points and then dichotomized into high/low fear or high/low impact according to the mean of the total points for each question.

All personal information was coded in order to avoid participants' identification. After importing the data from *Google Forms*, the descriptive analysis and logistic regressions were performed. The impact on their daily routine during the pandemic and fear of the dentist's IPE were the dependents variables. The method applied for

the logistic regression was the *Backward Stepwise*, with the independent variables with $p < .05$ included in the adjusted model. Values with $p < .05$ were considered statistically significant in the adjusted analysis. The results were obtained in odds ratio (OR) with a 95% confidence interval. All analyzes were performed using the software *Stata 13.0*.

3 | RESULTS

Among the 1072 responses, in the first week, 1064 responses were obtained, 783 in the first 24 h, and, in the second week, eight responses. Seventy one were excluded for presenting incomplete data. Table 1 illustrates the raw data from the questionnaire applied to these parents. The data after the dichotomization of the variables measured in the Likert Scale according to the means are illustrated in Table 2. Adding the scores of questions 1 to 4 (14.81 ± 3.58), in general, half of these parents had high fear of the pandemic by COVID-19 (50.3%). More than half of parents believe that the children/adolescents will be afraid to be treated by a dentist using the complete IPE (59.34%) and more than half of parents think that the situation associated with COVID-19 will affect the way their child deals with the daily routine (61.33%).

In Table 3, the adjusted and unadjusted analysis of the influence of fear of the dentist's IPE is illustrated. Parents of children/adolescents with ASD who responded that they were more fearful and anxious about taking their children to the dentist during the pandemic were 3.75 times (95% CI 2.86–4.91; $p < .000$) more likely to respond that their children would have fear of the dentist's IPE. Also, the children/adolescents in which the parents responded to having moderate/severe ASD, were 60% (95% CI 1.22–2.09; $p < .001$) more likely to respond that their children would be fear of the dentist's IPE compared to children/adolescents with mild ASD degree.

The adjusted and unadjusted analysis of the influence of impact on their daily routine during the pandemic is illustrated in Table 4. After adjusting the variables, it was observed that the children/adolescents in which the parents responded to having moderate/severe ASD, were 37% (95% CI 1.02–1.84; $p < .036$) more likely to have an impact on their daily routine during the pandemics compared children/adolescents with mild ASD degree. Also, children/adolescents in which parents responded that social interaction will have a greater impact after the pandemic were 10.49 times (95% CI 7.53–14.07; $p < .000$) more likely to have an impact on their daily routine during the pandemics compared to low impact.

TABLE 1 Descriptive variables of the questionnaire applied to parents of children and adolescents with autism spectrum disorder ($n = 1001$)

Variables	<i>n</i> (%)
Degree of ASD according to medical diagnosis reported by parents	
Mild	432 (43)
Moderate	481 (48)
Severe	88 (9)
Questions to parents about the COVID-19 pandemic	
1. I am very afraid of COVID-19 (by parents)	
Strongly disagree	29 (2.90)
Disagree	62 (6.19)
Do not agree nor disagree	188 (18.78)
Agree	421 (42.06)
Totally agree	301 (30.07)
2. I feel uncomfortable thinking about COVID-19	
Strongly disagree	53 (5.29)
Disagree	114 (11.39)
Do not agree nor disagree	195 (19.48)
Agree	436 (43.56)
Totally agree	203 (20.28)
3. I am afraid of losing my life because of COVID-19	
Strongly disagree	39 (3.90)
Disagree	98 (9.79)
Do not agree nor disagree	167 (16.68)
Agree	425 (42.46)
Totally agree	272 (27.17)
4. I get nervous or anxious when I see notices in the newspapers and social media about COVID-19	
Strongly disagree	68 (6.79)
Disagree	136 (13.59)
Do not agree nor disagree	243 (24.28)
Agree	403 (40.26)
Totally agree	151 (15.08)
5. My child would be afraid to be seen by a dentist garmented with individual protective equipment	
Strongly disagree	102 (10.19)
Disagree	305 (30.47)
Do not agree nor disagree	-
Agree	398 (39.76)
Totally agree	(19.58)
6. Would you be afraid and anxious if your child needs to go to the dentist during the Covid-19 pandemic?	

(Continues)

TABLE 1 (Continued)

Variables	<i>n</i> (%)
Strongly disagree	83 (8.29)
Disagree	249 (24.88)
Do not agree nor disagree	153 (15.28)
Agree	366 (36.56)
Totally agree	(14.99)
7. To what extent did the situation associated with COVID-19 affect the way the child deals with the daily routine?	
No impact	36 (3.60)
Little impact	118 (11.79)
Moderate impact	233 (23.28)
It impacted my son's life	254 (25.37)
It greatly impacted my child's life	(35.96)
8. Do you think your child's social interaction will have an impact after the pandemic?	
No impact	62 (6.19)
Little impact	173 (17.29)
Moderate impact	271 (27.07)
It impacted my son's life	271 (27.07)
It will greatly impact my child's life	(22.38)
9. Did your child have to go to the dentist during the pandemic?	
Not	728 (72.73)
Yes	(27.27)
10. If YES, what is the reason for the consultation? ^a	
Prevention	100 (36.63)
Treatment	162 (59.34)
Missing data	11 (4.03)

^aAnswers linked to the previous question

4 | DISCUSSION

This study aimed to evaluate the fear of parents of children/adolescents with ASD about the pandemic by COVID-19, as well as to report the possible fear about IPE in the dental appointment and the impact on the daily routine during and after the COVID-19 pandemic according to the degree of autism of the child/adolescent with ASD. Our results demonstrate that the majority of parents reported being afraid of the pandemic by COVID-19, children/adolescents' fear of the dentist's IPE, and high impact on the daily routine of children/adolescents during the pandemic by COVID-19. Parents who showed more anxiety and fear of taking their children to the dentist during the COVID-19 pandemic influence the perception of fear of children/adolescents with the use of IPE by dentists. The degree of moderate/severe ASD, according to those responsible, also influences the greatest fear

TABLE 2 Mean and standard deviation of the questions 1 to 8 question applied to parents ($n = 1001$)

QUESTIONNAIRE (Questions 1–8)			
Questions	General (Mean + SD) ^a	Low n (%)	High n (%)
1 to 4. Fear of the COVID-19 pandemic by parents	14.81 (3.58)	497 (49.65)	504 (50.75)
5. My child would be afraid to be seen by a dentist garmented with Individual Protective Equipment	3.90 (0.99)	(27.87)	722 (72.13)
6. Would you be afraid and anxious if your child needs to go to the dentist during the Covid-19 pandemic?	3.25 (1.21)	(48.45)	516 (51.55)
7. To what extent did the situation associated with COVID-19 affect the way your child deals with the daily routine?	3.78 (1.75)	387 (38.66)	614 (61.34)
8. Do you think your child's social interaction will have an impact after the pandemic?	3.42 (1.18)	506 (50.55)	495 (49.45)

^aMinimum = 1; Maximum = 5

TABLE 3 Association between the fear of the child/adolescent when being seen by a dentist such as IPE^a according to parents and variables related to the pandemic of the COVID-19 ($n = 1001$)

Variables	n (%)	Not adjusted		Adjusted	
		OR (95% CI)	p	OR (95% CI)	p
Fear of the COVID-19 pandemic by parents					
Low fear	497 (49.65%)	1		-	-
High fear	504 (50.75%)	1.03 (0.79–1.35)	.785	-	-
Fear and anxiety of the parents for taking the children/adolescent to the dentist during the COVID-19 pandemic					
Low fear	485 (48.4%)	1		1	
High fear	516 (51.5%)	3.75 (2.86–4.91)	.000 ^b	3.75 (2.86–4.91)	.000
Degree of ASD according to medical diagnosis reported by parents					
Mild	432 (43.2%)	1		1	
Moderate/Severe	569 (56.8%)	1.60 (1.22–2.10)	0.001 ^b	1.60 (1.22–2.09)	0.001

Abbreviations: OR, odds ratio; 95% CI, 95% confidence interval.

Significant at the level of 5%.

^aIPE (Individual Protective Equipment)

^bvariables with p value <.05 included in the adjusted model

of children/adolescents of the dentists' IPE. Also, children/adolescents with ASD in whom parents reported having suffered more impact on their daily routine during the pandemic believe that children will have a more social impact after the pandemic. The degree of moderate/severe ASD also seems to influence the greatest impact on the daily routine according to those responsible.

Most parents presented a significant level of fear the COVID-19 pandemic. This result may be related to social

isolation, anxiety, fear of contagion, uncertainty, chronic stress and economic difficulties as a consequence of the pandemic.¹⁵ In addition, the study by Ming et al. (2016)³² demonstrated that children with ASD may have reduced cardiac parasympathetic activity leading to respiratory dysrhythmia, being classified as a risk group for COVID-19. As a result, the fear of contagion can lead to an increase in the level of anxiety of those responsible for children and adolescents with ASD. However, it should be noted that most

TABLE 4 Association between the Impact on daily routine of children/adolescents during the pandemic and variables related to the pandemic of the COVID-19 ($n = 1001$)

Variables	n (%)	Not adjusted		Adjusted	
		OR (95% CI)	<i>p</i>	OR (95% CI)	<i>p</i>
Fear of the COVID-19 pandemic by parents					
Low fear	497 (49.65%)	1		-	
High fear	504 (50.75%)	1.24 (0.96–1.67)	.145	-	-
Social interaction on the life of children / adolescents after the COVID-19 pandemic					
Low impact	506 (50.5%)	1		1	
High impact	495 (49.5%)	10.28(7.52–14.05)	.000 ^a	10.29 (7.53–14.07)	.000
Degree of ASD according to medical diagnosis reported by parents					
Mild	432 (43.2%)	1		1	
Moderate/Severe	569 (56.8%)	1.39(1.03–1.88)	.027 ^a	1.37 (1.02–1.84)	.036

Abbreviations: 95% CI, 95% confidence interval; OR, odds ratio.

Significant at the level of 5%.

^avariables with *p* value <.05 included in the adjusted model

of the participants in our research were women, and they tend to report greater health concerns.¹⁶

In this study most of parents said that their children did not need to go to a dental appointment during the pandemic, and those who did, mostly had received some kind of treatment. In addition, most parents demonstrated being afraid to take their child to a dental appointment during the pandemic COVID-19. These findings corroborate with a recent study in which the authors reported a drop in the number of children's hospitalizations due to parents' fear of contracting the infection by the virus during the care.¹⁷ Guo et al.¹⁸ also demonstrated COVID-19 pandemic influenced the search for dental care, since most used services only in cases of dental emergency, as demonstrated in the present study. Furthermore Yang et al.¹⁹ reported that dental services were affected during the COVID-19 pandemic, because most preventive and non-emergency services were suspended, which may have consequences on the oral health of the population. Samuel et al.²⁰ in a retrospective study evaluated the number of pediatric dental emergencies during the pandemic by COVID-19. The authors demonstrated that there was a significant increase in the demand for emergency treatments, such as tooth extractions, which can be attributed to the parents' fear of going to a dental appointment and contracting the infection by the virus and, the decrease of professionals attending during the pandemic. These data alert to the emotional impact of dental pain in children as a result of the pandemic.

About the fear of children and the IPE used by dentists, most parents agreed that their child feels fear when treated. These results are important because they can help health professionals to seek alternatives to mitigate these factors and bring improvements in the dental care for children diagnosed with ASD and their parents. It is important to note that the initial perception of patients and parents in relation to health professionals based on their attire, facial expressions and body language can affect the patient's comfort level. Children often attribute pain and other negative experiences to the white coat and refuse to cooperate in medical and dental exams and consultations.^{21–24} A pathology called, "white coat hypertension" was defined as a temporary increase in blood pressure before and during the clinical visit, which can lead to discomfort. Thus, some parents associate the image of the dental surgeon using IPE with something that treats their child's fear and discomfort.¹⁰ In addition, the degree of severity of autism influenced the parents' perception of the fear of the child or adolescent regarding the IPE used by the dentist. This finding may be due to the fact that children who have greater communication difficulties tend to have uncooperative behavior during the consultation,²⁵ resistance to changes in the environment, and, the parents' greater anxiety to influence children's dental fear.²⁶ In this sense, the importance of using behavioral techniques, such as video, images, figures, to demonstrate the skills and procedures to be acquired and reduce anxiety before the dental appointment in children with autism.^{27,28}

On the other hand, the parents' fear may have influenced the response about the child/adolescent's fear about the dentist's IPE. In our study, there was an association between parents who were more afraid of taking their children to a dental appointments and greater fear of the dentist's IPE. Therefore, the results on the fear of the dentist's IPE by the child/adolescent must be interpreted with caution

In the matter of the impact on the daily routine of children, most of the parents stated that the pandemic had a significant impact on their children's lives during the COVID-19 pandemic and, this impact on routine may negatively influence the social interaction of the child/adolescent with ASD after the pandemic. This fact corroborates the idea presented in the study by Jepsen et al.²⁸ who reported that children and adolescents with attention deficit, hyperactivity and ASD, may be particularly prone to psychological suffering during the pandemic due to loss of daily routines. Children with special needs, such as autism spectrum disorder, usually require weekly interventions with therapists, psychologists, speech therapists, or in hospitals and institutes dedicated to this type of disorder. However, at the present time, due to restrictive measures in isolation, these children are instructed to stay at home to avoid contagion. Along with the change in routine, there is an increase in stress both on children who tend to have their lives changed by the pandemic, as well as on their parents due to exacerbation of behavioral problems. This fact can be corroborated with the study by Wong et al.²⁹, in which they demonstrated an increase in problematic behaviors and emotional problems caused by reduced social interaction in the quarantine, regressing the social skills of children with ASD. In addition, according to Narzisi et al.³⁰, children with ASD may have their stress levels elevated during the period of isolation, resulting in increased stereotypes.

It was observed in the present study that the degree of ASD also influenced the routine of children and adolescents, during the pandemic of COVID-19. Generally, the greater the severity of autism, the greater the child's difficulty in socializing and adapting to changes in the routine.¹¹ In this sense, the changes imposed by the pandemic, such as isolation¹⁵, may justify the greater social impact on these individuals.

This study has strengths and limitations. As for strengths, a sample calculation was performed, obtaining a significant size, as well a pilot study to evaluate the reliability of the questionnaire. Due to the COVID-19 pandemic and the impossibility of social contact, the number of online surveys has increased,³⁰ since questionnaires via the Internet can reach a significant number of people without the need for social contact. Another positive aspect of the present study, refers to the questionnaire

being relatively short, facilitating the acceptance by parents to answer the questions. As for limitations, cross-sectional studies cannot estimate causality between the variables and the outcome. Obtaining the degree of ASD of children / adolescents using the parents' report can also limit the results. Also, the use of online questionnaires based on the opinion of those responsible for children/adolescents with ASD and the convenience sample may influence the representativeness of the results, and the results must be interpreted with caution. For future studies, we suggest conducting longitudinal studies to assess the impact of pandemic COVID-19 in patients with ASD.

5 | CONCLUSION

We concluded in this study that, according to the parents' responses, they were afraid of COVID-19, and children or adolescents with ASD may be afraid when a dentist with IPE sees them. The perception of fear of children/adolescents about the IPE used by the dentist can be influenced by the fear and anxiety of parents regarding taking their child to a dental appointment during the pandemic and the degree of moderate/severe autism. The social impact on children's lives during the COVID-19 pandemic can be high, and these conditions can be influenced by the degree of autism and having an impact on social interactions after the pandemic. It is important to think of strategies that make the dental consultation an environment of well-being and safety, both for the child and for their parents. Making this moment more pleasant and less stressful. In addition, measures are needed to enable the re-socialization of these children and adolescents with ASD during and after the COVID-19 pandemic, so that the routine and social interactions are not affected.


ACKNOWLEDGMENTS

This study was supported by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) - (J.M. grant number 001).

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ORCID

Juliana Silva Moro  <https://orcid.org/0000-0001-9011-9600>

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How to cite this article: Azevedo Machado B, Silva Moro J, Massignam C, Cardoso M, Bolan M. Fear, changes in routine and dental care for children and adolescents with autism spectrum disorder in the COVID-19 pandemic: A survey with Brazilian parents. *Spec Care Dentist*. 2021;1–9. <https://doi.org/10.1111/scd.12683>