



Original Article

Development of a new tool for predicting the behavior of individuals with intellectual disability in the dental office: A pilot study



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ABSTRACT

Background: The dental treatment of individuals with intellectual disability can represent a considerable professional challenge.

Objective: To develop a model for predicting the behavior of patients with intellectual disability in the dental office.

Methods: The study group comprised 250 patients with Down syndrome (DS), autism spectrum disorder (ASD), cerebral palsy (CP), idiopathic cognitive impairment or rare disorders. We collected their demographic, medical, social and behavioral information and identified potential predictors (chi-squared test). We developed stratified models (Akaike information criterion) to anticipate the patients' behavior during intraoral examinations and to discern whether the dental treatment should be performed under general anesthesia. These models were validated in a new study group consisting of 80 patients. Goodness of fit was quantified with sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) and area under the receiver operating characteristic curve (AUC). We developed a mathematical algorithm for executing the models and developed software for its practical implementation (PREdictors of BEhavior in Dentistry, "PREBED").

Results: For patients with DS, ASD and CP, the model predicting the need for physical restraint during examination achieved a PPV of 0.90, 0.85 and 1.00, respectively, and an NPV of 0.66, 0.76 and 1.00, respectively. The model predicting the need for performing treatment under general anesthesia achieved a PPV of 0.63, 1.00 and 1.00, respectively, and an NPV of 1.00, 1.00 and 0.73, respectively. However, when validating the stratified models, the percentage of poorly classified individuals (false negatives + false positives) ranged from 24% to 46.6%.

Conclusions: The results of the PREBED tool open the door to establishing new models implementing other potentially predictive variables.

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Behavioral problems are one of the main barriers for individuals with special needs in accessing dental care and frequently represent a challenge for oral healthcare practitioners.^{1,2}

Although a number of authors have attempted to identify variables that could serve as "predictors of behavior" in the dental office, these variables were identified and assessed in isolation in

most studies published to date and were typically analyzed as univariate correlations.^{3–5} A number of authors have suggested that the following variables are predictors of the degree of cooperation in the dental chair: age, reading ability, sphincter control, presence of comorbidities, speech difficulties, behavior during various daily life activities (such as tooth brushing, cutting hair and dressing), combative behavior and the ability to perform group activities.^{4,6,7} To date, however, there is no consensus in the literature on the predictive value of these variables, with authors stating that there are numerous limitations such as obvious methodological biases, highly heterogeneous collections of studies

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and determinants inherent in the healthcare system and infrastructure, which preclude extracting reliable conclusions.^{3,4,7}

Studies have indicated that when managing patients with behavioral disorders, there is an overuse of deep sedation and general anesthesia techniques.^{2,8} A number of authors attribute this overuse to a lack of understanding of the patient's communication and learning characteristics and to poor planning of behavioral guidance techniques.^{2,8} In other cases, the referral to general anesthesia is based exclusively on the systemic diagnosis, without considering the patient's other characteristics.^{9,10} A number of researchers have sought to determine whether there are non-behavioral variables related to the demand for general anesthesia,^{3,11} but very few have included these variables among the decision-making criteria.¹² Authors such as Stiefel¹³ state that this investigation is crucial, while others such as Meurs et al.¹⁴ consider that the usefulness of this information is highly limited.

It has been suggested that having prior information on a particular patient not only allows for the development of preventive strategies but also facilitates the application of behavioral guidance tools and as a result, assists in improving the dental experience.^{4,15,16} However, there is still some controversy regarding the actual usefulness of collecting specific information on patients in advance, so as to intuit their degree of cooperation in the dental office, design individualized treatment plans and establish protocols for referral to specialist centers. The aim of this study was to develop a behavior prediction model that would help anticipate the behavior of patients with intellectual disability during intraoral examinations and dental treatments.

Methods

Study group selection

To develop predictive models, a study group (SG) of convenience was formed, consisting of 250 patients with intellectual disability who attended the Special Care Dentistry Unit (SCDU) at the Santiago de Compostela University (Spain) between January 2018 and February 2020.

The following inclusion criteria were applied to select the participants: first visit to the SCDU; 5–60 years of age (World Health Organization, 2016); intellectual disability according to the definition proposed by the American Psychiatry Association (APA, 2013), with a systemic diagnosis of intellectual disability of unknown origin (ID), Down syndrome (DS), autism spectrum disorder (ASD), cerebral palsy (CP) or rare disease (RD); and voluntary participation (informed consent signed by the patients' legal guardians).

To validate the predictive models developed in the first phase of this study, we created a validation group (VG) of convenience including at least 25 patients of each systemic diagnosis (DS, ASD and CP), selected by applying the same inclusion criteria. The VG ultimately consisted of 80 patients.

Recording of variables

The guardians were given a standardized questionnaire consisting of 30 items distributed among 6 sections: 1) demographic data; 2) socialization; 3) medical data; 4) presence of routines, habits and parafunctions; 5) behavior in daily life activities; and 6) behavior in other medical or dental consultations. Other predictors of behavior in the dental clinic listed in the literature were included.^{3,4,14} The full questionnaire is shown in [Table S1](#).

To assess the patient's behavior in daily life activities, we applied a modified version of the Frankl scale¹⁷ in which we used a value of 0 for the "not evaluable" conditions due to a lack of antecedents.

The response variables were: 1) the degree of cooperation when

performing an oral examination and 2) the need for performing the dental treatment under general anesthesia. To categorize the conditions of the oral examination, we proposed 2 options (without resorting in any case to drug sedation): 1) no physical restraint (there can be slight movements of one or several parts of the body, provided they do not need restraining and they do not prevent the intraoral examination) and 2) with physical restraint (it is necessary to firmly immobilize one or several parts of the body through restraint by one or several individuals and/or by the use of devices for this purpose). The need for performing the dental treatment under general anesthesia for behavioral reasons was recorded dichotomously (yes/no).

Study design and statistical analysis

The study was observational, cross-sectional and analytical and began by administering the questionnaire described above to the guardians, which took approximately 5 min to complete. The patient and their companion then entered the office, where the dental record was reviewed, and an intraoral and radiological examination was performed, recording information regarding the patient's behavior during these procedures. Once the results from all of the participants' questionnaires and examinations had been processed, we identified the variables significantly related to the patients' behavior (Pearson's chi-squared test). Significance level was considered at p-values <0.05. We developed an initial predictive "general" model for the described response variables applying multivariable logistic regression analysis with the Akaike Information Criterion (AIC),¹⁸ for which we maximized sensitivity and specificity simultaneously or used the chi-squared test.

We then created several stratified models based on the systemic condition. Applying the AIC, we showed that, for the patients with ID or RD, it was not possible to obtain models with sufficient predictive capacity. Therefore, the groups that were ultimately included in these stratified models were DS, ASD and CP. The selection criterion for assessing the relative quality of the stratified models was the lowest AIC, and the classification method was the chi-squared test.

The next phase consisted of validating the stratified models in the VG, which included at least 25 patients of each category (DS, ASD and CP), who were also administered the questionnaire and from whom information was collected on the patients' behavior in the clinic.

The prepared predictive models' goodness of fit was defined in terms of sensitivity, specificity, positive predictive value, negative predictive value, and area under the receiver operating characteristic curve. The data were statistically treated using the environment and language of R commander.¹⁹

Lastly, we developed a mathematical algorithm for executing the stratified models and an interactive software application for visualizing the results using the R Shiny package (<https://shiny.rstudio.com/>). We named the application "PREBED" (Predictor of Behavior in Dentistry).

The study was approved by the Ethics Committee of the University of Santiago de Compostela, Spain (reference: USC 11-4-2019).

Results

The members of the initial SG were 105 female (42%) and 145 male patients (58%), with a mean age of 23.0 ± 12.6 years (range 5–56 years). The most prevalent systemic conditions were ID ($n = 115$), ASD ($n = 39$) and DS ($n = 36$). Sixty-four percent of the participants routinely took medication, mainly psychotropic (33%) and antiepileptic drugs (30%).

Sixty percent of the participants were schooled in special education centers, and 27% attended non-specialized centers. Eighty-nine percent stayed overnight in the family home every night. Seventy percent regularly attended workshops, and 70% participated in group sports.

Noise and vibration tolerance was 66% and 70%, respectively; the lowest percentages were detected in DS (47% and 59%, respectively). Thirty-seven percent of the SG presented bruxism (47% in the DS group and 47% in the CP group). The habit of nibbling was present in 27% of the SG (29% in the DS group), and sucking was present in 8% (12% in the DS group).

The behavior was “definitely positive” in 73% of the individuals when having their hair cut, in 69% when having their nails trimmed, in 42% when being shaved/depilated, in 93% when dressing, in 91% when showering/cleaning up, in 93% when eating, and in 45% when brushing teeth (in 25%, the behavior was “negative” or “definitely negative”).

The behavior of the patients was “definitely positive” in 33% of the cases in which some blood test was performed (“positive” in 24%), in 47% of those who underwent extraoral radiographs and in 41% of those who underwent an electrocardiogram.

The behavior during the oral examination was positively and significantly correlated with the behavior exhibited during certain “daily life activities” such as haircut, nail trimming and tooth brushing (Table 1). There was also a statistically significant positive relationship between the behavior during the oral examination and that shown by the patient when undergoing “supplementary medical diagnostic tests” such as blood tests, extraoral radiography and electrocardiography (Table 1).

The need for performing the dental treatment under general anesthesia for behavioral reasons was significantly associated with noise and vibration intolerance (Table 1). Among the “daily life activities”, shaving/depilating and tooth brushing were also significantly and positively related to the degree of collaboration (Table 1). The need to resort to general anesthesia to achieve behavioral control was significantly correlated with all of the “supplementary medical diagnostic tests” used as reference (blood tests, extraoral radiography and electrocardiogram) (Table 1).

With the variables that correlated with the behavior exhibited by the patients in the dental office, we developed a general predictive model. To this end, the Frankl scale values had to be recoded, removing those variables with lost values and grouping the categories “definitely negative” and “negative”, due to the difficulty in discerning between the two options in this type of patient. The selection criterion for assessing the relative quality of the general model for predicting behavior during the oral examination was the lowest AIC (AIC = 293.897). The classification method attempted to simultaneously maximize the sensitivity and specificity. When applying this model, the percentage of misclassified individuals (false negatives + false positives) was 26.8%. To predict the need for performing the dental treatment under general anesthesia, we also applied the lowest AIC (AIC = 248.902). The classification method was the chi-squared test, and the percentage of misclassified individuals applying this model was 23.2%. Table 2 lists the goodness of fit results for the general model.

In the stratified models for predicting the behavior during the oral examination in the patients with DS, ASD and CP, the lowest AIC values were 32.574, 43.158 and 16.000, respectively. The percentages of misclassified individuals when applying these stratified models were 23.8%, 20.5% and 0%, respectively. In the stratified models for predicting the need for performing the dental treatment

under general anesthesia in the patients with DS, ASD and CP, the lowest AIC values were 27.590, 14.000 and 21.589, respectively. The percentages of misclassified individuals when applying these stratified models were 14.2%, 0% and 21.0%, respectively. Table 2 lists the goodness of fit results for the stratified models.

In the validation process for the stratified models for predicting the behavior during oral examinations of patients with DS (n = 25), ASD (n = 28) and CP (n = 27), the percentages of misclassified individuals were 40.0%, 46.4% and 40.7%, respectively. In terms of predicting the need for conducting the dental treatment under general anesthesia, the percentages of misclassified individuals were 24.0%, 32.1% and 37.7%, respectively.

The algorithm developed for executing the stratified models is outlined in Fig. 1.

Discussion

In this study, we developed behavior prediction models to anticipate the behavior of patients with intellectual disability in the dental office. Assuming that, in medicine, a diagnostic tool is considered effective when the specificity value exceeds 80%, the results with the stratified models were “good”, especially in the individuals with ASD and CP, although the tool's efficacy was not confirmed in the validation process.

The PREBED tool has a more practical and specific character in terms of the need for using general anesthesia than other available tools such as the International Classification of Functioning, Disability and Health (ICF)²⁰ and the British Dental Association (BDA) Case Mix Model.²¹ The ICF²⁰ includes components that can help predict patients' behavior empirically and based on the practitioner's expertise, but its potential for discriminating the need for administering general anesthesia has not been evaluated. The BDA Case Mix Model²¹ evaluates the relationship between the patient's behavior in daily life activities and in the dental office. The model also warns that the patients with the highest scores (the most complex patients) more frequently require general anesthesia when undergoing dental treatment but does not quantify the likelihood that a certain patient should be treated under general anesthesia. Lastly, the score that this tool assigns to each of the evaluated variables is based exclusively on the experience of the authors who developed it.²²

In the literature, we have found no other tool for predicting the behavior in the dental clinic that has a feedback mechanism and a graphical interface that allows immediate access to the software's results. The possibility of predicting patient behavior can be of considerable usefulness for optimizing resources (e.g., by selecting the most appropriate behavioral control techniques in each case),²³ for minimizing the number of unnecessary trips and for referring those patients to specialized units or to hospital departments where they will be treated under general anesthesia in a much more objective manner than with the only criterion of their systemic diagnosis.^{7,16} Another setting in which the PREBED tool can be used is in teaching,²⁴ to differentiate patients who can be treated by personnel undergoing training and those who should be attended by practitioners with specific postgraduate training.²⁵

The validation of the models did not confirm the results in the SG, which could be due, among other factors, to the limitations of the sample size and to the differences in age between the individuals in the SG and VG. Although the VG included at least 25 patients of each systemic diagnosis (DS, ASD, CP), certain outcome variables included only a few participants, such as 5 patients with DS and 8 with CP in whom the dental treatment was ultimately

Table 1
Predictors related to the patient's behavior during the oral examination and to the need to perform the dental treatment under general anesthesia (p < 0.05).

		Behavior during the oral examination (%) ^a			p
		Negative	Positive	Definitely Positive	
Behavior in daily life activities^a					
During haircut	N	16.3	9.1	0.0	<0.001
	P	32.6	9.1	5.7	
	DP	51.2	81.8	94.3	
During nail trimming	N	18.6	4.5	0.0	0.002
	P	32.6	9.1	17.1	
	DP	48.8	86.4	82.9	
During tooth brushing	DN	9.3	9.1	0.0	<0.001
	N	30.2	18.2	5.7	
	P	41.9	22.7	20.0	
	DP	18.6	50.0	74.3	
Behavior in other diagnostic tests^a					
When undergoing a blood test	NA	0.0	4.5	2.9	<0.001
	N	67.4	36.4	11.4	
	P	23.3	22.7	25.7	
	DP	9.3	36.4	60.0	
When undergoing extraoral radiography	NA	4.7	9.1	5.7	<0.001
	DN	11.6	4.5	2.9	
	N	34.9	22.7	0.0	
	P	27.9	22.7	8.3	
	DP	20.9	40.9	82.9	
When undergoing an electrocardiogram	NA	48.8	36.4	31.4	<0.001
	N	18.6	4.5	0.0	
	P	14.0	13.6	2.9	
	DP	18.6	45.5	65.7	
		Need for treatment under general anesthesia (%) ^a		p	
		No	Yes		
Presence of routines, habits and parafunctions^a					
Noise tolerance	No	25.4	55.2	0.005	
	Yes	74.6	44.8		
Vibration tolerance	No	22.5	48.3	0.015	
	Yes	77.5	51.7		
Behavior in daily life activities^a					
When shaving/depilating	NA	52.1	31.0	0.037	
	N	4.2	6.9		
	P	2.8	17.2		
	DP	40.8	44.8		
During tooth brushing	DN	1.4	17.2	<0.001	
	N	14.1	31.0		
	P	26.8	37.9		
	DP	57.7	13.8		
Behavior in other diagnostic tests^a					
When undergoing a blood test	NA	2.8	0.0	0.003	
	N	29.6	69.0		
	P	28.2	13.8		
	DP	39.4	17.2		
When undergoing extraoral radiography	NA	7.0	3.4	0.005	
	DN	4.2	13.8		
	N	14.1	34.5		
	P	16.9	27.6		
	DP	57.7	20.7		
When undergoing an electrocardiogram	NA	43.7	31.0	<0.001	
	N	4.2	20.7		
	P	4.2	24.1		
	DP	47.9	24.1		

^a We applied the Frankl scale; N, negative; P, positive; DP, definitely positive; DN, definitely negative; NA, not applicable; p, statistical significance.

performed under general anesthesia. The differences in age were particularly significant between the patients with DS in the SG and those in the VG (mean of 24.2 years vs. 31.7 years). In the individuals with DS, the behavioral patterns were determined by variables such as intellectual capacity and socio-environmental aspects.²⁶ The difference in age was also considerable between the patients with ASD in the SG and those in the VG (mean 15.1 years vs. 22.1 years). Although restricted and repetitive patterns of behavior and interests have been reported in individuals with ASD, there is considerable interindividual variability.²⁷ Lastly, it is

possible some of the patients included in the VG might have participated in a desensitization program that was started in our healthcare setting, coinciding in time with the conduct of this study. The diagnosis of intellectual disability in patients with CP should be based on objective assessments because it is easy to reach false conclusions.²⁸ This bias can worsen when the sample size is small. In the VG, for example, physical restraint was ultimately applied to only 9 individuals.

The present study has other methodological limitations that should be considered when interpreting its results. We employed

Table 2
Goodness of fit of the general and restricted models for predicting the patient's behavior in the dental office.

		Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)
General Predictive Model (n = 250)	Oral examination ^a	0.724 (0.647–0.792)	0.744 (0.644–0.829)	0.824 (0.745–0.872)	0.619 (0.531–0.730)	0.774 (0.712–0.836)
	General anesthesia ^b	0.631 (0.513–0.739)	0.790 (0.714–0.853)	0.615 (0.514–0.725)	0.801 (0.712–0.862)	0.757 (0.691–0.823)
Predictive Model for DS (n = 36)	Oral examination ^a	0.931 (0.772–0.991)	0.571 (0.184–0.901)	0.900 (0.603–0.987)	0.666 (0.334–0.931)	0.852 (0.723–0.982)
	General anesthesia ^b	1 (0.590–NA)	0.809 (0.580–0.945)	0.636 (0.363–NA)	1 (0.777–1)	0.963 (0.906–1.019)
Predictive Model for ASD (n = 39)	Oral examination ^a	0.666 (0.409–0.866)	0.904 (0.696–0.988)	0.857 (0.591–0.951)	0.760 (0.523–0.965)	0.860 (0.747–0.973)
	General anesthesia ^b	1 (0.735–NA)	1 (0.851–NA)	1 (0.749–NA)	1 (0.841–NA)	0.960 (0.900–1)
Predictive Model for CP (n = 25)	Oral examination ^a	1 (0.752–NA)	1 (0.735–NA)	1 (0.750–NA)	1 (0.737–NA)	1 (1–1)
	General anesthesia ^b	0.500 (0.157–0.842)	1 (0.715–NA)	1 (0.477–1)	0.733 (0.338–NA)	0.943 (0.85–1)

DS, Down syndrome; ASD, autism spectrum disorder; CP, cerebral palsy.

^a Degree of cooperation for performing an oral examination (with or without protective stabilization/physical restraint).

^b Need for performing the dental treatment under general anesthesia (yes or no); CI, confidence interval; PPV, positive predictive value; NPV, negative predictive value; AUC, area under the receiver operating characteristic (ROC) curve; NA, not applicable.

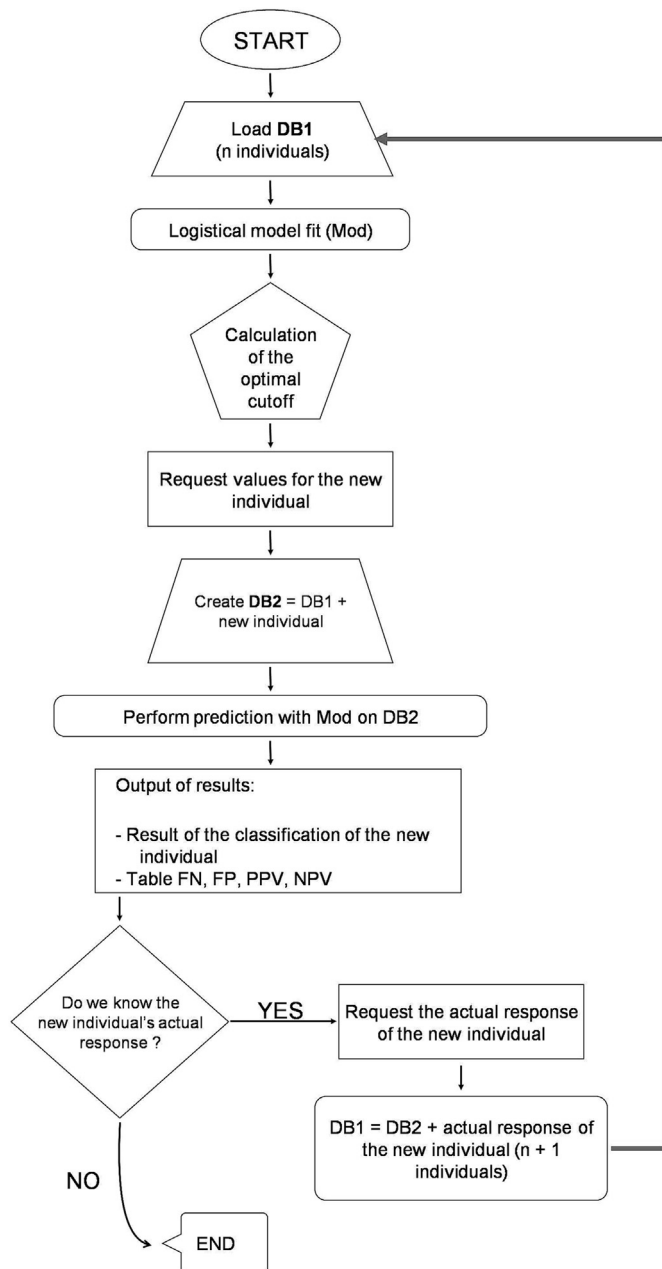


Fig. 1. Flow diagram and feedback of the PREBED tool (Predictors of Behavior in Dentistry). DB1, original database; Mod, adjusted model; DB2, database updated by inserting a new individual; FN, false negatives; FP, false positives; PPV, positive predictive value; NPV, negative predictive value.

a convenience sample, applying the sample size used in previous studies on this subject as a guide.²⁹ The size of this convenience series might have compromised the statistical power, which is why the title of this manuscript indicates that this is a pilot study; however, we did perform a *post hoc* statistical power analysis because it is a highly controversial practice that has been criticized as being conceptually defective.³⁰ The data collection from patients with disability through standardized interviews of their relatives and/or guardians has been a resource frequently used in the literature^{14,31,32} but can induce biases resulting from the subjectivity or misinformation of the interviewee. The behavior of certain patients is subject to significant variability, such that the behavior on the day of the consultation might not correspond to their everyday behavior. The behavior during the oral examination, as well as being determined by the circumstances of the patient, can be modified by factors inherent in the practitioner, such as their empathy, experience and skills in behavioral control.^{25,33} Although the PREBED program will indicate the performing of the treatment under general anesthesia, the clinician's training and experience should take precedence over the algorithm. Other options should also be considered such as desensitization sessions, premedication and protective stabilization, especially when the patient's requirements are of a preventive or minimally invasive nature such as routine prophylaxis.³⁴ Although the risks inherent in general anesthesia have ostensibly been reduced in recent years,³⁵ the procedure is not without complications that in exceptional cases can result in death. Its indication should therefore always be assessed in terms of the risk-benefit, taking into account the patient's necessary dental procedures and systemic conditions.³⁶ There are also other factors that can discourage performing the dental treatment of patients with special needs under general anesthesia (even in cases in which this technique is clearly indicated when applying tools such as PREBED), such as financial limitations and the lack of healthcare resources (operating room availability) and human resources (sufficiently qualified anesthesiologists).³⁷ In short, the final decision to conduct the dental treatment under general anesthesia is subject to factors such as the practitioner discretion and the available healthcare resources.^{7,16}

Conclusions

We present a new tool (PREBED) for predicting the behavior in the dental office, a tool that is very easy to use and provides an immediate quantitative response. The tool's reliability is determined by the specific characteristics of the professional applying the tool and by the characteristics of their work environment; however, the program's feedback system makes this reliability increase progressively. Accordingly, by applying this methodology,

we propose testing new determinants that help improve the model's goodness of fit and validate it in a variety of healthcare contexts, so that the model can be routinely applied in the healthcare system and teaching setting.

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Conflicts of interest

The authors declare no potential conflicts of interest with respect to the authorship and/or publication of this article.

Supplementary material

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