
Proposal of a psychosocial evaluation scale in peripheral facial paralysis

Proposição de uma escala de avaliação psicossocial na paralisia facial periférica

Propuesta de una escala de evaluación psicossocial en la parálisis facial periférica

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Abstract

Objective: To prepare a questionnaire that features the psychosocial aspects of subjects with peripheral facial paralysis (PFP). **Methods:** The elaboration of the Psychosocial Scale of Facial Appearance (PSFA) included literature review, collection of instruments that presented similar functions to the questionnaire, as well as critical analysis. The development of the issues sought to cover the diversity of the cases of PFP, the easy understanding of the respondent, both for its form and content. After the elaboration of the PSFA, 18 expert judges in the PFP actuation were selected to evaluate the questionnaire. An evaluation form was prepared and meetings were scheduled for the analysis of the PSFA. The data were descriptively analyzed and organized from convergent and divergent categories for subsequent final review. **Results:** The PSFA was effective when it allowed responding the research problem for which it was prepared, being essential the initial literature collection for theoretical background, knowledge, understanding and critical analysis of the existing instruments. The evaluation of the judges was essential for the improvement of the prepared instrument, simplification of the questions and improvements in future applications of the PSFA in a research group. **Conclusion:** This study showed preliminary data for the use of a new instrument for detecting psychosocial aspects in cases of PFP and such investigation is justified, since many subjects present significant impairments that may interfere in the clinical outcome.

Keywords: Facial paralysis; Evaluation; Psychosocial impact; Questionnaires.

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Resumo

Objetivo: elaborar um questionário que caracterize os aspectos psicossociais de sujeitos com paralisia facial periférica (PFP). **Método:** A elaboração da Escala Psicossocial de Aparência Facial (EPAF) contou com revisão bibliográfica, levantamento de instrumentos que apresentassem funções similares ao questionário, além de análise crítica. O desenvolvimento das questões buscou abranger a diversidade dos quadros de PFP, a fácil compreensão do respondente, tanto em relação à sua forma, quanto ao seu conteúdo. Após a elaboração da EPAF 18 juízes especialistas na atuação em PFP foram selecionados para avaliar a EPAF. Um formulário de avaliação foi elaborado e reuniões foram agendadas para análise da EPAF. Os dados foram analisados descritivamente e organizados a partir de categorias convergentes e divergentes, para posterior revisão final. **Resultados:** A escala mostrou eficácia quando permitiu responder ao problema de pesquisa para o qual foi elaborado, sendo essencial o levantamento bibliográfico inicial para fundamentação teórica, conhecimento, compreensão e análise crítica dos instrumentos existentes. A avaliação dos juízes foi primordial para o aprimoramento do instrumento elaborado, simplificação das perguntas e melhorias em futuras aplicações da EPAF em grupo de pesquisa. **Conclusão:** Este estudo mostrou dados preliminares para utilização de um novo instrumento para detecção de aspectos psicossociais nos quadros de PFP, e justifica-se tal investigação, visto que muitos sujeitos apresentam comprometimentos significativos que podem interferir na evolução clínica.

Palavras-chave: Paralisia facial; Avaliação; Impacto psicossocial; Questionários.

Resumen

Objetivo: Preparar un cuestionario que cuenta los aspectos psicossociales de los pacientes con parálisis facial periférica (PFP). **Método:** La elaboración de la Escala psicossocial de la apariencia facial (EPAF) incluye revisión de la literatura, colección de instrumentos que presentan funciones similares el cuestionario, así como el análisis crítico. El desarrollo de los temas trató de cubrir la diversidad de los casos de la PFP, la fácil comprensión de la parte demandada, tanto por su forma y contenido. Después de la elaboración del EPAF, se seleccionaron 18 jueces expertos en la actuación PFP para evaluar el cuestionario. Un formulario de evaluación fue preparado y reuniones se programaron para el análisis de la EPAF. Los datos se analizaron de forma descriptiva y organizados de categorías convergentes y divergentes para su posterior revisión final. **Resultados:** La EPAF fue eficaz cuando se permitió responder al problema de investigación para el que fue preparado, siendo imprescindible la colección bibliográfica inicial para el fondo teórico, el conocimiento, la comprensión y el análisis crítico de los instrumentos existentes. La evaluación de los jueces era esencial para la mejora del instrumento preparado, la simplificación de las preguntas y las mejoras en las futuras aplicaciones de la EPAF en un grupo de investigación. **Conclusión:** Este estudio mostró datos preliminares para el uso de un nuevo instrumento para detectar los aspectos psicossociales en los casos de PFP y dicha investigación se justifica, ya que muchos de los sujetos presentan alteraciones significativas que pueden interferir en el resultado clínico.

Palabras clave: Parálisis facial; Evaluación; Impacto psicossocial; Cuestionarios.

Introduction

One of the concerns in the elaboration of a research instrument is that it is useful to register or to approach the reality of the object of study¹.

When the aim of the search is to increase knowledge regarding aspects of a certain population, one can opt for a data survey, and the use of questionnaires may be appropriate for this purpose. The elaboration of a questionnaire is based on the research problem and, therefore, on the theoretical background and the variables to be determined^{2,3}.

The questionnaire is defined as an investigation technique that comprises a determined number of written questions presented to a selected group of people with the aim to know their opinions. The use of this technique has advantages, such as the possibility to achieve a great number of respondents and to avoid that they are influenced by the opinions of the interviewer. However, questionnaires may present unexpected results, since the items may have different meanings for each respondent. Another problem is the limited number of questions, for excessively long questionnaires have high probability to be inaccurate⁴.

To ensure quality in the elaboration of an instrument, it is essential to conduct a literature search on the theme in order to appropriate the theoretical background, to elaborate questions that are true to the proposed objective, to allow the instrument to be evaluated by selected experts, and to provide a final review, so the applicability and reproducibility of the instrument may be tested in pilot studies^{2,3,5}.

In this study, considering the theme to be investigated – the psychosocial impact of peripheral facial paralysis (PFP) –, the current literature was searched for studies on psychosocial aspects, describing the instruments used for this purpose.

It is known that impairments in psychical and social aspects cause several changes in the daily life of subjects with PFP. One of the consequences is that the process of clinical evolution itself may be hindered, if not well established, causing sequelae for the subject⁶⁻⁹.

The first literature finding evaluated the efficacy of the Facial Disability Index (FDI), elaborated by the Facial Nerve Center¹⁰. This instrument was translated into Brazilian Portuguese as *Índice de Incapacidade Facial* (IIF). As in the original version, the instrument is subdivided into two sections:

the first corresponds to the Physical Function Index (PFI), and the second, to the Social/Well-being Function Index (SWBFI). The FDI has been used in Brazil for some studies: after myofunctional therapy in patients with PFP, with self-assessment from two different groups, submitted and not submitted to the application of botulinum toxin¹¹; with the aim to measure the degree of perception and discomfort regarding the facial condition of subjects with long-term PFP¹²; and correlated with electromyography results, in order to investigate treatment outcomes¹³.

As evidenced above, the Brazilian Portuguese version of the FDI has been used a lot; however, the instrument has not yet been through cross-cultural adaptation and the validation process in Brazil, which may be questioned in its methodological aspects¹⁴. Moreover, in the studies mentioned, the results obtained did not reveal significant results regarding subjective perception, and tended to evidence how the patient sees his physical condition, with little relationship between degree and severity of the impairment¹¹⁻¹³.

In another study, the psychical aspects (anguish, stress, and self-esteem) of 103 patients with PFP resulting from acoustic neuroma surgery were evaluated. These subjects were assessed using four different instruments: 1) Derriford Appearance Scale (DAS), which has the aim to measure the anguish associated with concerns regarding physical appearance; 2) COPE Questionnaire, which measures manners to deal with stress; 3) *Facial Paralysis Questionnaire* (FPQ), which measures the quality of facial functions; and 4) personal report. The results evidenced high levels of anguish, especially in subjects with low self-esteem, young people, women, and subjects living alone. The study also showed that these levels of anguish were not directly associated with the degree of impairment caused by PFP. Therefore, how the patients felt about themselves, with respect to their self-image, possibly prevailed over the nature of their own reactions, or even the severity degree of the PFP¹⁵.

The most recent instrument, the *Facial Clinimetric Evaluation Scale* (FaCE)¹⁶, has been culturally and linguistically adapted by Portuguese researchers¹⁷, contributing to its validation into Portuguese. The results of their study showed the efficacy of the cross-cultural adaptation of the instrument, which was translated as *Escala de*

Avaliação Facial Clinimétrica para o Português; however, it was emphasized that the applicability of the questions was more adequate in the initial stage of the facial condition of PFP, and not in stages with longer duration. Nevertheless, to be used in Brazil, a new cross-cultural and linguistic adaptation would be necessary.

To evaluate the effects of intervention carried out with PFP patients, the satisfaction and the impact on quality of life must be considered. For this reason, a systematic review was conducted, with the aim to identify validated instruments designed to assess the quality of life of patients with PFP. The survey found 598 published articles and identified 28 questionnaires. However, only three instruments met the selection criteria: 1) FaCE; 2) DAS; and 3) FDI. Results showed that, although the instruments' development and validation were described, none of the measures met all the guidelines for this purpose. Moreover, the instruments are restricted to the domains of self-perception of facial appearance and symptoms, or satisfaction with the rehabilitation process, which limits their use¹⁸.

As mentioned, the studies had the purpose to present functional, psychical and quality of life self-assessment instruments for subjects with PFP. However, their limitations include valuing one aspect over others and/or not being able to comprehend all the PFP cases, not considering the duration of the condition, etiology and/or severity degree.

Thus, it is justified the development of a questionnaire that includes the psychosocial aspects implied in PFP cases and that has the aim to consider the greatest possible number of people affected by this condition, attending different etiologies, severity degrees, and duration of the condition. With this in mind, the aim of this study was to develop a questionnaire to characterize the psychosocial aspects of subjects with PFP.

Methods

Structure of the questionnaire

- a) **Format:** Font type and size and the questionnaire structure were chosen having in mind the aim to facilitate the respondent's visualization.
- b) **Name:** The questionnaire was named Psychosocial Scale of Facial Appearance – PSFA (*Escala Psicossocial de Aparência Facial – EPAF*).
- c) **Identification and history:** Space reserved to

complete with the subject's full name and the date when the questionnaire was fulfilled.

- d) **Initial instructions:** Instructions were presented before the questionnaire; they were designed to be clear, objective, and easy to understand.
- e) **Elaboration of questions and review:** The writing style was simple, so to facilitate the respondent's comprehension. Then the text was reviewed for grammar errors, redundancy, and complexity.
- f) **Number of questions:** Initially, the PSFA had 21 questions.
- g) **Thematic groups:** The PSFA was divided into three thematic groups: 1. Functional facial aspects; 2.1. Social aspects – Task performance; 2.2 Social aspects – Social interactions; 2.3. Social aspects – Marital relationship; 3. Emotional aspects. Each thematic group had 7 questions.

Response format

For this study, we opted for closed responses, in which the respondent selects the option that is closest to his opinion, among the possible answers presented. For this purpose, a Likert scale – which presents ordered categories equally spaced and with the same number of categories in all items – was used.

Thus, for each question, the subject should choose only one number among the four possible response categories:

- 3 = Always/Completely agree;
- 2 = Sometimes/Partially agree;
- 1 = Rarely/Don't remember;
- 0 = Never/Disagree.

Meeting with the judges

As part of the requirements for validation, the questionnaire was evaluated by selected judges, who are experts in PFP, in order to determine whether the resulting PSFA was according to the purposes of the research.

The selection of judges considered their scientific and clinical contributions in PFP, acknowledged in the professional community.

Initially, 14 judges were invited to participate, and 9 answered to the invitation. These judges were also asked to indicate other colleague experts, and each of them suggested at least one other name.

Finally, the list had 23 invited judges, and 18 of them accepted to be part of the study.

The meetings were then scheduled. Judges were provided with the PSFA and an evaluation protocol, which had the aim to verify the questionnaire's structure and its efficacy in assessing the population it was aimed to study in the future. For this purpose, the evaluation protocol comprised the following items:

- time taken to fulfill the questionnaire;
- difficulty to understand some questions;
- different meanings for the same expression;
- clarity and accuracy of the instructions provided;
- differentiation of the possible answers;
- contributions for adaptation of the questions;
- questions that should be included;
- questions that should be removed; and
- adequacy of the font type and size used in the questionnaire.

The protocol items were developed based on theoretical elements in order to determine the apparent validity of a questionnaire^{19,20}.

Data analysis

After the meeting with the judges, a descriptive analysis was conducted by organizing convergent and divergent categories²¹. With the organization of categories, each question and thematic group was reviewed and had its relevance to the research analyzed. After five meetings, it was possible to determine the changes and adjustments necessary to improve the questionnaire. Finally, the PSFA went through a final spelling check.

Results

Questionnaire

The questionnaire was effective to answer the research problem it was designed to. The initial literature review was essential to provide theoretical background, knowledge, understanding and critical analysis of the existing instruments.

A necessary attention was given to the writing of the questions, so they conveyed the desired meaning to obtain the expected results. We acknowledged the risk that the respondent had a different interpretation, and, therefore, the evaluation of judges who were experts in PFP was an

important step in the development process of the instrument.

The initial version of the Psychosocial Scale of Facial Appearance (PSFA) presented 21 questions – a non exhaustive number –, divided into three categories or thematic groups: 1. Functional facial aspects – questions 1 through 7; 2. Social aspect, subdivided into 2.1. Social aspects – Task performance – questions 8 through 11; 2.2 Social aspects – Social interactions – questions 12 and 13; and 2.3. Social aspects – Marital relationship – question 14; 3. Emotional aspects – questions 15 through 21.

The structure of the PSFA had the intention to conduct the subject from general to more specific, and from less to more personal, and this order was applied to the thematic groups. The first questions established a relationship of trust between respondent and researcher^{2,3}, and the following questions investigated the impact of the psychosocial aspects on the PFP.

The initial version presented a space for the respondent's identification, the date when the questionnaire was fulfilled, and the time taken to do it. Moreover, a brief version of the objective and the instructions to complete the PSFA were also presented (Appendix 1).

The option for a gradual Likert scale with four categories had the aim to avoid confusions with the category in the middle, since, in five-category scales, subjects have the tendency to select it when confused or unsure. This format had the intention to make the subjects assume a position.

Judge analysis

The group of judges comprised 16 speech-language pathologists (89%), one otorhinolaryngologist (5.5%) and one psychologist (5.5%). In average, they had 11.7 years of work with PFP (SD = 9.1, median = 10 years, ranging from 1 to 27 years).

Due to the difficulty to arrange the meetings with all judges at the same time, the researcher met them at their own institutions, with the commitment to provide an update regarding the suggestions from previous meetings.

Five meetings were conducted, with number of participants ranging from one to five. The judges were associated to one out of five university institu-

tions, and four of them offered outpatient care to patients with PFP.

The group agreed that: the time spent to complete the PSFA – estimated at 15 minutes – was adequate; the instructions presented were clear and accurate; and the differentiation between possible answers were adequate.

Regarding the format of the PSFA, judges suggested an increase in the font used, to facilitate the visualization of respondents.

Considering the population studied, they agreed that some questions should be adjusted in order to make them more simple to understand and to be clearer regarding their objectives. In some cases, the initial version of the question was subdivided into two questions for the later version, according to the analysis of the judges.

Other questions were suggested to be added to the questionnaire, and the relevance of questions 20 and 21 were discussed by some judges. After the researcher explained these questions, they agreed to keep them after some adjustments to make them clearer.

The adjustments and modifications made to the PSFA are grouped in Chart 1. They are described based on the questionings presented on the evaluation protocol, when they did not reach 100% agreement between the judges.

After the conclusion of this stage, it was conducted an analysis that considered the judges' contributions, according to the research purpose. A new version of the PSFA was then elaborated, followed by a final review, carried out by the researcher herself.

The final questionnaire presented 24 questions, and the thematic groups "social aspects" and "emotional aspects" were adjusted, as described: 2. Social aspects; 2.1. Task performance – questions 9 to 12; 2.2. Social interactions – questions 13, 14, 17 and 18; Emotional aspects – questions 15, 16, and 19 to 24.

The order of the questions kept the precepts mentioned in Methods, and treated the subject from more general to more specific aspects, establishing, initially, a relationship of trust with the patient and then moving to more delicate questions, regarding social and emotional aspects.

Chart 2 presents the questions that shaped the instrument, based on the comparison between the initial and final versions.

The final version of the Psychosocial Scale of Facial Appearance (PSFA) is presented in Appendix 2. The initials of the theme groups are presented next to the questions, in order to facilitate their identification.

Discussion

Data from the studies presented in the Introduction – which had the purpose to investigate self-perception, psychosocial and quality of life aspects related to PFP as general purpose or part of a research process –, overall, showed few evidence for comparison with the severity degree of the facial function impairment or the duration of the condition of the PFP10-13.

There are only few instruments to evaluate the effects of intervention and subjective contents regarding PFP¹⁸, and they present limitations for the purposes of this study. Hence, we developed an instrument to measure the psychosocial implications involved in PFP conditions. The development of the instrument was relevant, as it reached the scientific accuracy that was necessary to constitute the PSFA.

It is known that actually recording the reality using an instrument such as a questionnaire is complex¹⁻³. It must address the research problem, present a number of questions that is not exhaustive to the respondent, be easy to understand, and reach an expressive sample of the population, without being biased, that is, the questionnaire cannot reflect the researcher's opinion, and must be theoretically based regarding the subject that it intends to study²⁻⁴.

Therefore, it has been emphasized the need for previous evaluation of an instrument, and the use of proper techniques for that purpose strengthens it⁵. One of the techniques consists on the evaluation by experienced judges, which, in this case, was primordial and decisive for the final improvement of the questionnaire. The contributions offered by this group of experts evidenced similar opinions, even though the evaluation meetings did not occur at the same moment for all judges (Chart 1).

The evaluation by judges contributed, mainly, to improve and simplify the final writing of the questions, in order to facilitate the respondents' comprehension. Thus, some questions were carefully analyzed to be improved before the questionnaire can be used for future pilot studies Chart 2.

Chart 1. Description of the questions that were adjusted, according to the judges' comments and suggestions

Evaluation protocol	Observations and suggestions
2) Some questions were difficult to understand. In case this happened, explicit which ones.	Question 3: Necessary to reformulate to make it clearer and more simple. Question 4: There is a problem related to the fact that it is specific to the possible sequelae from PFP, and may not attend all the cases. However, most judges would not suppress the question. Question 5: Present examples of speech sounds. Question 6: Split the question into the functional aspect of masticatory and swallowing functions and the lack of will to feed due to sadness. Question 7: Make it clear that the difficulty to express is due to the muscle movement. Question 20: Necessary to make it clear that the patient must refer to the moment immediately prior to the PFP.
3) I believe that some expressions used in the questionnaire have multiple meanings, which may hinder the patients to complete them properly.	Question 4: Necessary to simplify it so it is shorter and cannot have different interpretations. Question 14: Remove the word "affectively". Question 16: Simplify to: "I suspect that my face will not get better". Question 18: Change to: "I get sad or distressed when I cannot show my emotions using facial expressions". Question 20: Make it clear that, in this question, the attribution of sadness, anguish, stress and/or anxiety must be associated to the PFP.
6) Would you provide other contributions to the adaptation of the questionnaire?	Question 5: Present examples of speech sounds. Question 7: Include that the question refers to the difficulty to express emotions through the face, since there are other factors related to the expression of emotions. Question 11: Make it more generalized. Instead of using the word "school", use "classes/courses", since the questions are directed to adults. Suggestion: If the patient is illiterate, the interviewer must read each item.
7) Are there other questions that you would include in the questionnaire?	Question 3: Split into two questions, since it concerns different difficulties. Suggestion 1: Include a question regarding pain in the face. Although pain has an organic aspect, it may affect the mood and be associated to emotional aspects. Suggestion 2: Include discomfort related to the difficulty to smile. Suggestion 3: Include the attribution of a score from 0 to 10 for the face.
8) Are there any questions that you would remove from the questionnaire?	Question 3: Feeding may include the swallowing of liquids, suction and chewing. The question regarding feeding could be subdivided. Question 20: The question seems a bit biased, as it may induce the subject to think that these factors are determinant for the occurrence of the disease. Knowing the physiopathology of the disease, it is known that stress may influence its occurrence, but there are several other factors that may cause it.
9) Are font type and size adequate to the questionnaire?	Increase font size.
10) Additional information.	Include: "Are there any questions that you think is important and was not asked?". Suggestion: Include the attribution of a score from 0 to 10 for the face.

Conclusion

This study was based on the hypothesis that the psychosocial aspects involved in PFP cases contribute to the understanding of clinical cases and may complement the speech-language pathology practice. Therefore, it is important to open up the space for such questions.

With the aim to provide subsidies and back up the professionals, this study purposed the development and the evaluation of the sensitivity of an instrument in the form of a questionnaire, designed to evaluate the psychosocial aspects involved in PFP cases.

In the task to develop the items for the questionnaire, the main psychosocial aspects associated to PFP in literature were mapped. Hence, it was possible to elaborate the questions and order them according to thematic groups, so they could be later analyzed by the judges.

The evaluation by experts was primordial for the discussion of relevant aspects, simplification of the questions, and improvements on the development of the questionnaire.

This study evidenced the preliminary steps towards the use of this new instrument. However, it is important to emphasize that the continuation of the study with the PSFA will include a pilot study and its application in groups of patients with PFP in

Chart 2. Comparison between the initial and final versions of the questions included in the PSFA.

Q	Initial version	Q	Final version
1	I have difficulty moving my face.	1	I have difficulty moving my face.
2	I have difficulty blinking or closing my eyes.	2	I have difficulty blinking or closing my eyes.
3	I have difficulties keeping the food in my mouth, using mouthwash, smiling or kissing.	3	I have difficulties keeping the food in my mouth.
		8	I have difficulties kissing.
4	There are movements that I do not desire to happen, such as: the eyes closing while I smile/speak, tearing up while I chew something, and/or moving the lips while I close my eyes.	5	When I speak, smile, chew and/or close my eyes, there are movements in my face that I cannot control.
5	I have difficulty pronouncing some words.	4	I have difficulty pronouncing words with 'p', 'b', 'm', 'f', 'v', 'sh' and 'g'.
6	I have lost my will to eat.	16	I have lost my will to eat.
7	I cannot express emotions.	7	I cannot express emotions through my face.
-		6	I have pain in my face.
8	I have difficulties going out of the house, visiting family and/or friends.	9	I have difficulties going out of the house, visiting family and/or friends.
9	I get uncomfortable appearing in photographs.	10	I get uncomfortable appearing in photographs.
10	I get uncomfortable eating in front of people.	11	I get uncomfortable eating in front of people.
11	I cannot go to work and/or school.	12	I get uncomfortable going to work and/or participating in classes/courses.
12	I get uncomfortable talking face to face with people.	13	I get uncomfortable talking face to face with people.
13	I feel comfortable only with close people from my social circle.	14	I feel comfortable only with close people from my social circle.
		15	The difficulty to smile bothers me.
14	I have difficulties to have an affective relationship with my partner, or, if I do not have a partner, to start a relationship with someone.	17	I have difficulties having a relationship with my partner, or, if I do not have a partner, starting a relationship with someone.
15	I realize that my family and friends now treat me differently.	18	I realize that my family and friends now treat me differently.
16	I suspect that I will have my current facial appearance forever.	19	I suspect that my face will not get better.
17	It makes me uncomfortable realizing that people who don't know me look at me differently.	20	It makes me uncomfortable realizing that people who don't know me look at me differently.
18	I feel sad or distressed when I cannot show my facial expressions.	21	I feel sad or distressed when I cannot show my emotions through facial expressions.
19	I do not have the will to take care of my appearance.	22	I do not have the will to take care of my appearance.
20	I remember that, before the change in my face, I felt sad, anguished, stressed and/or anxious.	23	I suspect that the change in my face is related to a prior event of sadness, anguish, stress and/or anxiety.
21	I remember feeling scared, desperate and/or distressed when I saw the change in my face.	24	I remember feeling scared, desperate and/or distressed when I saw the change in my face.
Note:			
	Kept		Modified or added

order to improve the design and achieve the necessary accuracy, so that the validation processes are effective and speech-language pathologists may use the instrument with PFP cases.

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Appendix 1. Initial version of the PSFA

Psychosocial Scale of Facial Appearance (initial version)

NAME: _____ Date: ____/____/____ Time taken: _____

This questionnaire will help us understand the impact of the physical changes in your face on your emotional and social life.

Please, answer all the questions related and, in case you have doubts, feel free to ask. If you would like to add complementary information, use the space at the end for your comments.

Circle ONLY ONE NUMBER, considering the LAST WEEK	Always	Sometimes	Rarely	Never
1) I have difficulty moving my face.	3	2	1	0
2) I have difficulty blinking or closing my eyes.	3	2	1	0
3) I have difficulty keeping the food in my mouth, using mouthwash, smiling or kissing.	3	2	1	0
4) There are movements that I do not desire to happen, such as: the eyes closing while I smile/speak, tearing up while I chew something, and/or moving the lips while I close my eyes.	3	2	1	0
5) I have difficulty pronouncing some words.	3	2	1	0
6) I have lost my will to eat.	3	2	1	0
7) I cannot express emotions.	3	2	1	0
Circle ONLY ONE NUMBER, considering the LAST WEEK and the ASPECT OF YOUR FACE	Always	Sometimes	Rarely	Never
8) I have difficulties going out of the house, visiting family and/or friends.	3	2	1	0
9) I get uncomfortable appearing in photographs.	3	2	1	0
10) I get uncomfortable eating in front of people.	3	2	1	0
11) I cannot go to work and/or school.	3	2	1	0
12) I get uncomfortable talking face to face with people.	3	2	1	0
13) I feel comfortable only with close people from my social circle.	3	2	1	0
14) I have difficulties to have an affective relationship with my partner, or, if I do not have a partner, to start a relationship with someone.	3	2	1	0
15) I realize that my family and friends now treat me differently.	3	2	1	0
16) I suspect that I will have my current facial appearance forever.	3	2	1	0
17) It makes me uncomfortable realizing that people who don't know me look at me differently.	3	2	1	0
18) I feel sad or distressed when I cannot show my facial expressions.	3	2	1	0
19) I do not have the will to take care of my appearance.	3	2	1	0

Circle ONLY ONE NUMBER	Totally agree	Partially agree	Do not remember	Disagree
20) I remember that, before the change in my face, I felt sad, anguished, stressed and/or anxious.	3	2	1	0
21) I remember feeling scared, desperate and/or distressed when I saw the change in my face.	3	2	1	0

Use the space below or the verse of the sheet to add complementary information:

Appendix 2. PSFA after judges evaluation

Psychosocial Scale of Facial Appearance

NAME: _____ Date: ____/____/____

This questionnaire will help us understand the impact of the physical changes in your face on your emotional and social life.

Please, answer all the questions related and, in case you have doubts, feel free to ask. If you would like to add complementary information, use the space at the end for your comments.

	Circle ONLY ONE NUMBER, considering the LAST WEEK and the ASPECT OF YOUR FACE	Always	Sometimes	Rarely	Never
FAF	1) I have difficulty moving my face.	3	2	1	0
FAF	2) I have difficulty blinking or closing my eyes.	3	2	1	0
FAF	3) I have difficulties keeping the food in my mouth.	3	2	1	0
FAF	4) I have difficulty pronouncing words with 'p', 'b', 'm', 'f', 'v', 'sh' and 'g'.	3	2	1	0
FAF	5) When I speak, smile, chew and/or close my eyes, there are movements in my face that I cannot control.	3	2	1	0
FAF	6) I have pain in my face.	3	2	1	0
FAF	7) I cannot express emotions through my face.	3	2	1	0
FAF	8) I have difficulties kissing.	3	2	1	0
SA -TP	9) I have difficulties going out of the house, visiting family and/or friends.	3	2	1	0
SA -TP	10) I get uncomfortable appearing in photographs.	3	2	1	0
SA -TP	11) I get uncomfortable eating in front of people	3	2	1	0
SA -TP	12) I get uncomfortable going to work and/or participating in classes/courses.	3	2	1	0
SA - SI	13) I get uncomfortable talking face to face with people.	3	2	1	0
SA - SI	14) I feel comfortable only with close people from my social circle.	3	2	1	0
EA	15) The difficulty to smile bothers me.	3	2	1	0
EA	16) I have lost my will to eat.	3	2	1	0
SA - SI	17) I have difficulties having a relationship with my partner, or, if I do not have a partner, starting a relationship with someone.	3	2	1	0
SA - SI	18) I realize that my family and friends now treat me differently.	3	2	1	0
EA	19) I suspect that my face will not get better.	3	2	1	0
EA	20) It makes me uncomfortable realizing that people who don't know me look at me differently.	3	2	1	0
EA	21) I feel sad or distressed when I cannot show my emotions through facial expressions.	3	2	1	0
EA	22) I do not have the will to take care of my appearance.	3	2	1	0



	Circle ONLY ONE NUMBER	Totally agree	Partially agree	Do not remember	Disagree
EA	23) I suspect that the change in my face is related to a prior event of sadness, anguish, stress and/or anxiety.	3	2	1	0
EA	24) I remember feeling scared, desperate and/or distressed when I saw the change in my face.	3	2	1	0

* **From 0 to 10, how would you rate your face today? (0 very bad and 10 very good)**

* **Besides these questions, are there any more information you would like to add?**

Legend: Functional aspects of the face (FAF); Social aspects – Task performance (SA – TP); Social aspects – Social interactions (SA – SI); Emotional aspects (EA).

