

Quality of life, work ability, and facial deformities

Qualidade de vida, capacidade para o trabalho e deformidades faciais

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ABSTRACT | Background: The face plays a central role in interpersonal relationships. Individuals with congenital or acquired facial deformities might experience difficulties with interpersonal relationships. Treatment should seek to improve their quality of life and work ability. **Objective:** To analyze the health-related quality of life and work ability of individuals with facial deformities. **Method:** Study with mixed, quantitative and qualitative methods. We conducted semi-structured interviews on health-related quality of life and its implications for work with 16 individuals with facial deformities, eight cases of congenital and eight of acquired deformities, cared at specialized services in Salvador, Bahia, Brazil. The Work Ability Index (WAI) and 36-Item Short-Form Health Survey were administered. **Results:** Thematic analysis led us to detect two categories of themes associated with facial deformities: interpersonal relationships and work ability; and quality of life and access to treatment. The participants with acquired facial deformities exhibited lower educational level and income, and lower quality of life and WAI scores compared to the ones with congenital deformities. All the participants with congenital deformities had received some form of rehabilitation and their social relationships were less impaired. **Conclusions:** Individuals with acquired facial deformities exhibited poorer work ability and quality of life compared to the ones with congenital deformities. Early rehabilitation of congenital deformities seems to considerably improve work ability and health-related quality of life.

Keywords | quality of life; work capacity evaluation; maxillofacial abnormalities; rehabilitation.

RESUMO | Introdução: A face exerce papel central nas relações interpessoais. Pessoas com deformidades faciais adquiridas ou congênitas tendem a apresentar dificuldades nas relações interpessoais. O tratamento desses pacientes deve visar à melhoria de sua qualidade de vida e da capacidade para o trabalho. **Objetivo:** Avaliar a qualidade de vida relacionada à saúde e a capacidade para o trabalho de pessoas com deformidades faciais. **Método:** Estudo misto de abordagem qualitativa e quantitativa. Entrevistas semiestruturadas sobre qualidade de vida em saúde e implicações no trabalho foram realizadas com 16 pessoas com deformidades faciais, oito congênitas e oito adquiridas, procedentes de serviços de atenção especializada de Salvador, Bahia. Aplicaram-se os questionários Índice de Capacidade para o Trabalho (ICT) e 36-Item Short-Form Health Survey. **Resultados:** A análise temática permitiu identificar duas categorias associadas às deformidades faciais: relações interpessoais e capacidade para o trabalho; e qualidade de vida e acesso a tratamento. Indivíduos com deformidades faciais adquiridas apresentaram menor escolaridade, renda e índices mais baixos nos indicadores de qualidade de vida e ICT, quando comparados aos do grupo com deformidades congênitas. Todos com deformidades congênitas receberam algum tipo de reabilitação e apresentaram menor comprometimento das relações sociais. **Conclusões:** Pessoas com deformidades faciais adquiridas apresentam maior comprometimento da sua capacidade para o trabalho e qualidade de vida do que aquelas com deformidades faciais congênitas. A reabilitação precoce das anormalidades congênitas parece exercer papel importante na melhora dos índices de ICT e de qualidade de vida em saúde.

Palavras-chave | qualidade de vida; avaliação da capacidade de trabalho; anormalidades maxilofaciais; reabilitação.

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INTRODUCTION

The face plays a central role in the initial establishment of social relationships, expression of feelings and communication. Due to such functional and social relevance, facial deformities are a cause of anguish and isolation. The quality of life of individuals with facial deformities was recognized in the past decade as an essential aspect of their treatment¹. These individuals might exhibit speech and swallowing problems, are more susceptible to anxiety disorders, and have more difficulty to develop affective and social bonds^{1,2}.

The notion of health-related quality of life (HR-QOL) of individuals with disabilities points to the effects of the corresponding functional and mental abnormalities on their perception and autonomy, as well as to their social opportunities for rehabilitation. The well-being of individuals with deformities should be the first priority of rehabilitation, even above the biomechanical and physiological outcomes. Facial deformities might be congenital or acquired after accidents and/or trauma, among which congenital cleft lip and palate, and defects after tumor resection or accidents and stand out¹⁻³.

Work ability represents the physical, mental and social capacity, and educational and social aspects involved in the performance of a job activity. It can be measured by means of the Work Ability Index (WAI) which thus enables early detection of potentially disabling abnormalities among aging workers, and the implementation of the corresponding preventive actions⁴.

Although the potential of facial deformities to influence the quality of life of the affected individuals is recognized in the literature, there is scarce qualitative and quantitative information to ground clinical judgment and the health professionals' understanding of the patients' social context. Therefore, the aim of the present study was to analyze the HR-QOL of individuals with facial deformities and its occupational implications.

METHOD

The present study with mixed methods was conducted from May 2014 through March 2015 at Saint Anthony Hospital and the traumatology outpatient clinic of

Federal University of Bahia, Brazil. Qualitative analysis considered QOL, health and occupational aspects, which were investigated by means of audio recorded semi-structured interviews, in which we approached the following subjects: facial deformities, work ability and HR-QOL. Eligible individuals were consecutively invited to participate in the study during visits to the aforementioned services. The sample size was established based on data saturation, i.e., the point in which sampling more data did not result in more information. The inclusion criteria was presence of facial deformities and age over 18 years old.

An informed consent form was read aloud before the participants were requested to sign it. Data collection was performed in a secluded room to ensure privacy and confidentiality. The interviews were audio recorded, then subjected to thematic analysis⁵. In this type of analysis, semantic structures are associated to sociological structures, and analysis of narratives is articulated with the factors which determine their characteristics, such as psychosocial variables, in addition to the context and process of production of messages. We sought to detect meaning units relevant to the study aims. A theme is a meaning unit extracted from the text under analysis.

Analysis evolved along three phase. Phase 1 was pre-analysis, which consisted on unfocused reading and thorough acquaintance with the material. In this stage, we established the record and context units and the most general theoretical notions to guide analysis. In phase 2, the record units were identified and encoded. The final phase involved treatment and interpretation of the results obtained.

In addition to the interviews, we administered three questionnaires:

- An ad hoc instrument for sociodemographic variables;
- WAI⁶;
- HR-QOL questionnaire Medical Outcomes Short-Form Health Survey (SF-36)⁷, license no. QM025904.

WAI comprises 10 main questions corresponding to seven domains⁶:

- Current work ability;
- Work ability in relation to the demands of the job;
- Number of current diseases self-reported or diagnosed by a physician;

- Estimated work impairment due to diseases;
- Sick leaves;
- Own prognosis on work ability;
- Mental resources.

Results provide a measure of work ability (WA) from the respondents' perspective; the total score ranges from 7 to 49, and are categorized as follows:

- Low (score 7 to 27): restore WA;
- Moderate (score 28 to 36): improve WA;
- Good (score 37 to 43): support WA;
- Optimal (score 44 to 49): maintain WA.

SF-36 comprises 36 items corresponding to eight domains:

- Physical capacity;
- Physical role functioning;
- Bodily pain;
- General health perception;
- Vitality;
- Social role functioning;
- Emotional role functioning;
- Mental health.

The items in each subscale are encoded, clustered and scored on a scale from 0 (worst) to 100 (best). The scores were normalized using software QualityMetric Health Outcomes Scoring Software 4.0. Normalization is a standardization procedure for statistical adjustment; in this case, the mean value for each domain was set to 50 with standard deviation of 10, thus generating two summary measures: Mental Component Summary (MCS) and Physical Component Summary (PCS)⁷.

The present study was approved by the research ethics committee of Saint Anthony Hospital, Salvador, Bahia, Certificate of Presentation for Ethical Appraisal (Certificado de Apresentação para Apreciação Ética – CAAE) no. 17021313.0.0000.0047, in compliance with the guidelines and standards for research involving human beings established in the National Health Council Resolution no. 466/2012 and the 2013 Declaration of Helsinki.

RESULTS

The sample comprised 16 participants, eight with acquired (AFD) and eight with congenital (CFD) facial

deformities. Group AFD comprised three women and five men, with average age 34 years old, ranging from 27 to 63. Group CFD comprised four women and four men, with average age 39.5 years old, ranging from 18 to 47. The sociodemographic and occupational characteristics of the participants are described in Table 1. The average income was lower for group AFD, BRL 988.00 (BRL 70.00 to 2,364.00) versus BRL 2,111.00 (BRL 800.00 to 5,500.00) for group CFD.

Qualitative analysis allowed detecting the following categories of themes related to the QOL and work of individuals with facial deformities: interpersonal relationships and WA (Table 2) and QOL and access to treatment (Table 3).

Participants from both groups reported having been victims of prejudice, which points to their relational vulnerability (Table 2) as illustrated by the following transcripts:

The lil' blind? Yes, it happened, always the mockery... I don't pay attention to what they say, I can see better than them. I can see beyond... When I was discharged from the hospital I wanted to jump from a height (AFD 1);

Everywhere I go people keep staring at me... I can't do my job in this way... I never saw my coworkers again after surgery. They went away (AFD 8);

Speaking is my worst problem, so... I prefer to keep quiet... It's difficult for me to communicate... Neighbors are prejudiced (CFD);

I try not to talk to anyone... I only talk when someone talks to me... My nose is ugly and I'm ashamed. I don't come close to people I don't trust (AFD 4).

WA differed between the groups. Five of the eight participants in group AFD, none of whom had undergone rehabilitation, scored low on WAI. In turn, WA was rated good for five and moderate for two participants in group CFD — all of whom had undergone some type of rehabilitation treatment (Table 2). The following are

transcripts from patients from AFD with low scores on WAI, and from CFD with high scores on WAI:

I can do just a few things... I don't shave alone not to get cut... I didn't go back to work. I never could (AFD 2);

I quitted school due to prejudice... I attempted a civil servant job, one of the slots for the disabled, but they called someone else. I filed a lawsuit. The secretary asked, 'So, are you able?' (AFD 3);

I was a bus driver. People ask: 'Does this bus go to such and such place?' How can I do my job? I can't communicate. I avoid places with too many people (AFD 4);

I couldn't speak well, they asked me to say again... Now I'm more self-confident! When someone doesn't get my name, I repeat it slowly. The government should make room (CFD 6);

Because I work with children, some people don't accept, and give me nicknames such as twisted mouth... Honestly, I don't care about the nicknames... It was quite easy to get [the job]. I have an education, right? But disrespect in the classroom: no! Just because of the cleft? (CFD 7).

Association analysis of interviews and SF-36 scores allowed analyzing the participants' access to rehabilitation and their understanding that healthcare is the government's responsibility. All participants with AFD

Table 1. Characterization of the sample of individuals with facial deformities, Salvador, Bahia, 2015 (n=16).

Deformities	N	Age	Sex	Educational level	Occupation	Deformities
AFD	1	63	M	Elementary school	Bus driver assistant	Orbital exenteration
	2	27	M	Elementary school	Farmer	Orbital exenteration
	3	28	F	Secondary school	Civil servant	Temporomandibular joint ankylosis
	4	39	M	Elementary school	Driver	Mandibulectomy
	5	27	M	Elementary school	Welder	Ear amputation
	6	28	F	Elementary school	Housemaid	Hemimaxillectomy
	7	27	M	Elementary school	Supermarket cashier	Facial polytrauma
	8	33	M	Elementary school	Construction worker	Mandibulectomy and glossectomy
CFD	1	47	f	Secondary school	Supermarket cashier	Bilateral transforaminal cleft
	2	45	M	Secondary school	Painter	Unilateral post-foraminal cleft
	3	45	M	Secondary school	Tire repairman	Unilateral post-foraminal cleft
	4	18	M	Elementary school	Administrative assistant	Bilateral transforaminal cleft
	5	47	M	Higher education	Journalist	Bilateral transforaminal cleft
	6	39	F	Secondary school	Medium-level technician	Bilateral transforaminal cleft
	7	29	F	Higher education	Teacher	Bilateral transforaminal cleft
	8	46	F	Higher education	Teacher	Unilateral preforaminal cleft

AFD: acquired facial deformities; CFD: congenital facial deformities; M: male; F: female.

Table 2. Facial deformities and their implications for interpersonal relationships and work ability, Salvador, Bahia, 2015 (n=16).

N	Narratives of participants with AFD	WAI	N	Narratives of participants with CFD	WAI
1	The lil' blind? Yes, it happened, always the mockery... I don't pay attention to what they say, I can see better than them. I can see beyond... When I was discharged from the hospital I wanted to jump from a height	L	1	Speaking is my worst problem, so... I prefer to keep quiet... It's difficult for me to communicate... Neighbors are prejudiced	G
2	I can do just a few things... I don't shave alone not to get cut... I didn't go back to work. I never could	L	2	When a teen they saw me differently at school, they mocked me... When a teen, before surgery, they mocked me, but I didn't have any problem at work	G
3	I quit school due to prejudice... I attempted a civil servant job, one of the slots for the disabled, but they called someone else. I filed a lawsuit. The secretary asked, "So, are you able? They don't always understand what I say, and are embarrassed to ask me to repeat it more than once... at office parties, where everybody goes, I keep quiet in a corner	M	3	I got problems with HRM at the job, because I couldn't avoid the nicknames... It was very troublesome, only in time I learned to defend myself	M
4	I was a bus driver. People ask: 'Does this bus go to such and such place?' How can I do my job? I can't communicate. I avoid places with too many people	L	4	My nose is ugly and I'm ashamed. I don't come close to people I don't trust I try not to talk to anyone... I only talk when someone talks to me... Everybody has patience, tries to listen, to understand what I say	G
5	People are too prejudiced, they keep asking what happened... Not everybody treats one alike. If I had the ear it would be different, right? I got a job, got enrolled, but it was quite hard to get it	L	5	There's people who avoid you, avoid looking you in the eyes, they even stop talking... communicating is difficult sometimes, some sounds people don't understand when they don't make an effort... I was bullied, but I don't care. I'm good in what I do and I'm respected... Affirmative action is important to get opportunities	O
6	Now the pain is different. I lost a part of my face, my teeth and my job. I lost my job. Honestly, I wouldn't be able to stand staying there... I just do house chores, sometimes I feel I want to be useful	M	6	I couldn't speak well, they asked me to say again... Now I'm more self-confident! When someone doesn't get my name, I repeat it slowly. The government should make room, but on the other hand people aren't aware, they don't want to help	G
7	My mom found they needed a cashier and that there was a slot for disabled people. I'm happy I can work, although I don't like the job... My mom's my best friend. She sees inside me, not my appearance... I have few friends [at the workplace] they don't want to come close	M	7	Because I work with children, some people don't accept, and give me nicknames such as twisted mouth... Honestly, I don't care about the nicknames... It was quite easy to get [the job]. I have an education, right? But disrespect in the classroom: no! Just because of the cleft?	G
8	Everywhere I go people keep staring at me... I can't do my job in this way... I never saw my coworkers again after surgery. They went away	L	8	The issue is education, it's the only way to do away with prejudice. When you have some disability, they think you're disabled, even to work... They give us nicknames, I feel I'm inferior and I'm sad at work... I want no one stares at me... I don't look people in the eyes	M

AFD: acquired facial deformities; WAI: Work Ability Index; CFD: congenital facial deformities; L: low (7-27); M: moderate (28-36); G: good (37-43); O: optimal (44-49); HRM: human resources management.

had received some form of rehabilitation, surgery or prostheses. For the participants from CFD, PCS fell within the mean and 1 standard deviation (Table 3). The same was the case of MCS, except for patient CFD 7, in which

the score (6.6) was considerable below the mean value. This participant had only received partial rehabilitation and still had a cleft lip. Her narrative denoted suffering and social stigma, which added to the negative impact of

Table 3. Quality of life and access to treatment among individuals with facial deformities, Salvador, Bahia, 2015 (n=16).

AFD				CFD			
N	Narratives	SF-36		N	Narratives	SF-36	
		PCS	MCS			PCS	MCS
1	One waits, right? We know we have to wait, right? We need the government, we depend on them to get help for people without means	47.02	60.14	1	There's no chance to get treatment like I get here paid by SUS where I live, in the interior [of the state]. But for this you have to have conditions to stay in the capital	51.71	46.33
2	In the interior [of the state] there was no ophthalmologist. I had a jaw fracture, there was no doctor to see such cases... Here I got good care. The problem is the delay!	44.61	16.94	2	I lived in the interior [of the state] and didn't have any information. My mom didn't know what to do. I was taken to a public university for treatment	55.64	57.17
3	For people who live in the interior [of the state] and need [treatment], it's very difficult. Too much humiliation. I needed a titanium prosthesis. The doctor said it would take about two years to get it	42.96	6.6	3	The only problem is the delay... In the beginning it was hard. Then I found out I had to arrive very early to get an appointment. I could overcome the barrier	47.66	45.06
4	When he saw the test results the doctor scheduled the operation earlier! Does it have some solution? I want to get rid of this mask	56.29	62.24	4	Everybody treats me well, with no exception... There are no meals. They're expensive, not everybody can pay for them	45.94	50.49
5	Care delivery is good here. Also at the clinical hospital is excellent... but it was hard. I needed to try a lot	28.04	41	5	My dad was afraid. A doctor said palate cleft surgery with a bone graft is risky for children. So he waited and waited, and I never had the second operation. But I wear a prosthesis. I was able to participate and make choices, but it's not always like this	57.09	56.51
6	The problem is what was left [sequelae]! More places with doctors and dentists who know how to treat problems like mine are needed	38.07	37.11	6	There were no speech therapists in Porto Seguro. I could not attend all the visits... but I tried to	58.04	57.08
7	They only spoke about what it had happened and what had to be done. One has to trust, right? I've already received plastic surgery, but I need more, and it's very hard to get it from SUS	45.06	31.39	7	I don't know why I have cleft lip ... I've heard it's difficult to get a slot [for treatment] in Bauru, and here it takes too long	74.19	13.14
8	I was always treated well, people are helpful, polite... They said I wouldn't be able to chew. I thought it would be temporary, but it wasn't	35.09	19.26	8	I always received information and chose what was best... We understand it's difficult. One must simply wait	41.29	53.6

AFD: acquired facial deformities; CFD: congenital facial deformities; SF-36: Medical Outcomes Short-Form Health Survey; PCS: Physical Component Summary; MCS: Mental Component Summary; SUS: Unified Health System.

incomplete surgical rehabilitation and poor knowledge about her condition.

The following transcripts illustrate the participants' perception of accessibility to health services, autonomy, knowledge about their health problem, access to rehabilitation and its influence on HR-QOL:

There's no chance to get treatment like I get here paid by SUS [Unified Health System] where I live, in the interior [of the state]. But for this you have to have conditions to stay in the capital (CFD 1, PCS 51.71; MCS 46.33);

My dad was afraid. A doctor said palate cleft surgery with a bone graft is risky for children. So he waited and waited, and I never had the second operation. But I wear a prosthesis. I was able to participate and make choices, but it's not always like this (CFD 5, PCS 57.09; MCS 56.51);

I don't know why I have cleft lip... I've heard it's difficult to get a slot [for treatment] in Bauru, and here it takes too long (CFD 7, PCS 74.19; MCS 13.14).

In regard to group AFD, MCS was much below the mean value for five participants, and in one further case it was close to the standard deviation limit (MCS 41.00). The following are transcripts of the narratives of the former:

For people who live in the interior [of the state] and need [treatment], it's very difficult. Too much humiliation. I needed a titanium prosthesis. The doctor said it would take about two years to get it (AFD 3, MCS 6.6);

The problem is what was left [sequelae]! More places with doctors and dentists who know how to treat problems like mine are needed (AFD 6, MCS 37.11);

I was always treated well, people are helpful, polite... They said I wouldn't be able to chew.

I thought it would be temporary, but it wasn't (AFD 8, MCS 19.26).

In two cases MCS was above the mean: one patient was concluding eye rehabilitation (MCS 60.14) and the other was in the stage of surgical planning for mandibular reconstruction (MCS 62.24).

In regard to PCS, three participants who had not yet reached the stage of rehabilitation planning exhibited scores below the mean. One had a maxillary deformity with a fistula (PCS 38.07), another mandibular and tongue deformity impairing speech (PCS 35.09) and the third a deformity secondary to traumatic ear amputation (PCS 28.04).

DISCUSSION

To the best of our knowledge, the present was the first study performed in Brazil which analyzed HR-QOL and WA among individuals with facial deformities. The resource to qualitative methods enabled us to investigate possible causes for the low scores obtained. WA differed between the groups, being lower for AFD, none of which participants had undergone rehabilitation. Differently, WA was rated good for five of the eight participants in group CFD, which had undergone at least partial rehabilitation. This difference might be attributed to the sudden loss of the face by the participants in group AFD, with consequent impairment of functions and senses needed for the performance of work activities, in addition to the discrimination they suffered⁸. These findings agree with the ones of other studies^{8,9}, which point to the influence of the stomatognathic system function on the quality of life after radical head and neck treatments. In both groups, moderate WA was associated with bullying; participants reported having experienced embarrassing situations at the workplace due to their deformities, powerlessness, and discrimination, all of which exert deep impact on individuals.

Income and educational level were lower for AFD, which information is significant, as the participants in this group exhibited less autonomy in the activities of daily living and poorer access to health care (Table 3).

Reports of poor accessibility, delay to receive treatment and/or permanent sequelae were frequent among the participants from group AFD with low MCS. Most of the difficulties met by participants from group CFD could be overcome. Only one patient had not attained esthetical rehabilitation of cleft lip, and her HR-QOL was severely impaired. The higher educational levels, with consequent better income, exhibited by group CFD might probably be associated with the fact rehabilitation had started in childhood. Rehabilitation had considerable influence on the HR-QOL of the participants with CFD, which agrees with the results of other studies which assessed the QOL of individuals with maxillary defects after prosthetic rehabilitation and surgical reconstruction by means of other instruments⁹⁻¹¹. In the present study, group AFD — not having undergone rehabilitation — exhibited lower raw and normalized scores on all SF-36 domains. In turn, for group CFD — which had undergone rehabilitation — MCS and PCS were higher, except for the one patient with non-corrected cleft lip.

The social context is extremely relevant for understanding our object in the present study. In agreement with the results reported by Liu et al.⁸ the present study evidenced that QOL was poorer among individuals with facial deformities, and that this is due to the combination of physical deterioration and mental anguish — indicated by high levels of anxiety, depression and social phobia, and poor self-esteem. The participants' narratives corroborated the quantitative data, and evidenced the degree of vulnerability of the patients. As a result, they contribute to the understanding of QOL as the interaction between external living conditions and the internal perception of individuals⁷.

The health provider-patient relationship was favorable in both groups. However, comparative analysis of WAI indicated that the autonomy of individuals with facial deformities was strongly associated rehabilitation, which has more weight than a favorable health provider-patient relationship. Thus, it should be considered in public health policies to achieve adequate biopsychosocial inclusion. The main complaints found in the present study concerned access to rehabilitation treatment, and especially the long duration of treatment. These complaints involve the understanding that the full scope of health care is the government's responsibility from access to the completion of rehabilitation, which clearly points to need to comply with SUS universality and equity principles. Quality of life should be considered an umbrella notion mandatorily encompassing all the aspects of medical care available for integral treatment³. Gaps in coverage increase vulnerability, as is seen in the participants' narratives.

CONCLUSION

The quantitative and qualitative results of the present study evidence a broad scope of problems met by patients, including poor access to rehabilitation treatment. Individuals with congenital or acquired facial deformities are exposed to conflicting interpersonal relationships as a function of the deformities and their social stigma. Individuals with AFD tended to exhibit poorer WA and physical and mental HR-QOL. Early rehabilitation of congenital deformities seems to contribute to increase WA and HR-QOL. Strengthening health policies to promote the rehabilitation and social inclusion of individuals with facial deformities is necessary.

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