

Ciências da Saúde no Brasil: Impasses e Desafios

7



Isabelle Cerqueira Sousa
(Organizadora)

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APRESENTAÇÃO

A coleção “Ciências da Saúde no Brasil: Impasses e Desafios” é uma coletânea composta de nove obras, e no seu sétimo volume apresenta uma variedade de estudos que versam sobre análises de dados epidemiológicos, como por exemplo: - Análise do perfil epidemiológico da sífilis congênita na região Centro Oeste do Brasil entre 2013-2018, - O perfil epidemiológico e a mortalidade de idosos internados por desnutrição no Tocantins entre 2014- 2019 utilizando Sistemas de informações em saúde do DATASUS, - Cenário epidemiológico da coqueluche em um distrito sanitário do Recife, Pernambuco, 2008 A 2017.

Nessa edição teremos também pesquisas que apresentam: - Plano de contingência para enfrentamento e controle da Dengue, Zika e Chikungunya e para enfrentamento e controle de hepatites B e C, - Dados epidemiológicos da febre amarela 2016-2018, da Doença de Chagas na Bahia, Brasil (2015-2019), - Plano de Ação contra Leptospirose em Belém – PA, - Aspectos laboratoriais da Leishmaniose, - Comparação entre os resultados de campanhas de detecção de Bócio em transeuntes voluntários de uma praça central de ribeirão preto, SP- (2013 a 2019), - Concepções dos profissionais de saúde sobre tuberculose na cidade de São Gonçalo, Rio De Janeiro.

Será demonstrada uma análise com projeção censitária indígena para o planejamento das políticas de saúde, um estudo sobre contaminação microbiológica em telefones celulares, será descrito um trabalho sobre: Desfiguração facial - uma abordagem multidimensional: teoria e modelos.

Essa obra também oportuniza leituras sobre a gestão de conflitos e combate às manifestações de violência em escolas públicas de Barcarena (Pará – Brasil), sobre epidemiologia das internações por câncer de cabeça e pescoço nos últimos 5 anos no brasil,

E ainda dando continuidade aos estudos e discussões sobre temas correlacionados ao câncer, teremos os seguintes trabalhos: - Análise da correlação da apoptose e o câncer: moléculas inibidoras das proteínas antiapoptóticas, - Uso da vitamina d no tratamento do câncer e influência de polimorfismos genéticos, - Imunoterapia no câncer de mama, - Acesso ao diagnóstico e tratamento de câncer de mama no estado do Piauí, - Aplicação da Escala Misscare em um serviço de oncologia: uma contribuição à segurança do paciente, - Magnitude da mortalidade por câncer cérvico uterino, - Análise epidemiológica da aplicação global de diferentes políticas públicas de combate ao câncer cervical.

Então, diante do percurso de aprendizado sobre tantos temas das ciências da saúde, a Editora Atena presenteia os leitores com esse volume que apresenta assuntos tão importantes de epidemiologia, tratamentos, processo saúde-doença, saúde pública e coletiva.

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CAPÍTULO 13

FACIAL DISFIGUREMENT - A MULTIDIMENSIONAL APPROACH: THEORY AND MODELS

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ABSTRACT: **Aim:** The adjustment to facial disfigurement (acquired or congenital) has been researched during the last few years, the objective of this work is to understand the main theories and models used by researchers in the course of their evaluation and intervention on people who show visible differences to their visage. **Method:** Using the EBSCO, Web of Knowledge, PubMed and Web of Science databases, an advanced research targeting facial disfigurement, theories, models and frameworks, was conducted. **Results:** The EBSCO, Web of Knowledge, PubMed and Web of Science databases identified 14 articles with the keywords “Facial disfigurement”, “Theory”, “Model” and “Framework”. These articles mention different approaches such as social, psychoanalytical, cognitive,

behavioural, stress and coping, biomedical and psycho-social. **Conclusion:** Most articles indicate the cognitive-behaviour theory as the one mostly used for evaluation and intervention on people with facial disfigurement.

KEYWORDS: Facial Disfigurement, Theory, Model, Framework.

INTRODUCTION

According to Elks (1990), it is necessary to have a physical characteristic altered enough to define facial disfigurement, which can cause a negative reaction in the individual or others, to one or a set of facial features. This author argues that without this negative reaction, a facial deviation is simply a visible difference and not a disfigurement. (Rumsey & Harcourt, 2004, 2005) argue that disfigurement is marked by the difference of a culturally defined norm that is visible to others.

Body image is influenced by a complex interaction between variables that influence perception, wherein the social culture, it is also built through models disseminated by the media that define values that shapes body image. On the other hand, interpersonal experiences, affected by expectations, opinions, verbal and non-verbal communication transmitted in the interaction that is established with family members, friends, peers and even strangers affect the development of the body image. Also important is the influence of the personality while

building one's attitudes that are directed to their body image (T. F. Cash, 2004). Facial disfigurement (acquired or congenital) is characterized but not solely defined by an alteration in a body image that is taken as regular.

The face is considered to be an organ that expresses emotions, which continuously appeals or rejects contact with others as a link between the individual and its surroundings (Adsett, 1963; Dropkin, 1999), allowing for the affirmation of human individuality as it distinguishes one from the other (DieeTrill & Straker, 1992; Elks, 1990). The face also identifies a person as it is the most visible part of the body (Bonanno & Choi, 2010; Dropkin, 1999; Soni et al., 2010; Tagkalakis & Demiri, 2009). Faces express the inner self and characteristics of the personality (Callahan, 2004), being a means for social interaction (Bonanno & Choi, 2010) and to communicate with the outside world (Soni et al., 2010).

A facial expression portrays physical and psychological well-being of a person, revealing emotions and/or concerns (tired, bored, sad, etc.). Thus the face plays a relevant role in interventions and in the making of social opinions (mainly regarding the first sight of a face) as when people meet for the first time they particularly focus on the face (Elks, 1990). However, Harris (1997) describes appearance as dynamic and subject to constant alterations throughout one's life span.

Although during the last two decades, facial disfigurement has been the target of much attention by the scientific community (Rumsey & Harcourt, 2005), its definition is not simple (Alves, 2016). Elks (1990) defends the existence of a necessary characteristic to define facial disfigurement "*the strength of negative reaction by the possessor, and others, to a particular facial feature, or set of features*" (pp.37), reinforcing that without this negative reaction a facial alteration is simply a difference and not a disfigurement. Henry (2011) mentions that when one suffers a real facial alteration (by sickness/trauma), one increases the tension between the real and the ideal body, thus making it difficult to precisely describe what disfigurement is, because not all those who have scars and marks on their faces are disfigured.

Various works have been developed during the last decades with the objective of understanding the psychological characteristics inherent to the adjustment of facial disfigurement. Nonetheless, the identification of its nature and the prevalent problems that originate from facial disfigurement are influenced by various factors (Clarke et al., 2014; Lansdown et al., 1997; Rumsey & Harcourt, 2012, 2005), and for this reason, the research done on individuals with visible differences has been centred in distinctive perspectives (Lansdown et al., 1997).

As individuals are idiosyncratic beings, it isn't easy to apply just one theoretical model that allows the adjustment of the individual to an alteration in its body image because the facts implied in this disfigurement process are not completely known. In this area, the grand dilemma to appropriately choose a model or theory as a guide for an investigation is to be centred in the limitations and the difficulties that are part of the evaluation of the

various dimensions that influence appearance (Rumsey & Harcourt, 2004).

Thompson (2012) mentions that a model or a theory is not sufficient when researching appearance as these are included in various areas (body image, attraction, disfigurement and identity), and it is not expected that a single approach will deal with all the aspects of human experience. For example, Cash and Pruzinsky (2004) refer the sociocultural, the psycho-dynamic, the information processing, the cognitive-behavioural and the feminist perspectives as possible forms of understanding body image. Rumsey and Harcourt (2004) mention, for instances, that the social cognition model is useful to examine treatment aspects and implicit health care that is directly related to appearance; the theory of self-regulation is focused on the understanding of distress and in behaviours related to duration, cause, cure and identity of individuals who have visible differences; the stress and coping theory explain the recovery of an individual after an aesthetic or reconstructive surgical intervention.

If concerns with appearance are multifactorial and the individual well-being regarding one's appearance is influenced by mood swings, including optimism and specific cognition of one's appearance (Thompson, 2012), this work aims at the understanding of which theories, models, and frameworks are mostly used in the research of adjustments to facial disfigurements.

METHOD

EBSCO, Web of Knowledge, PubMed and Web of Science databases were used in this advanced research ranging from 1960 to 2016. Only articles from Psychology and Behavioural Sciences Collection were analysed. Table 1 shows the advanced research made with the Boolean method and the inclusion and exclusion criteria. The keywords "*Disfigurement, Theory, Model and Framework*" were used in the search criteria that included All text (TX), Title (TI), and Subject terms (SU). The keyword "Framework" was included in the search as some authors use it instead of "Model".

For the inclusion/exclusion criteria we only considered peer reviewed articles that were completely available, focused on visible changes and presented a theory or model related to facial disfigurement.

After excluding doubled articles, we narrowed down the research to 14 articles. Table 2 makes a brief analysis of those articles.

Type of Research	Keywords				Number of results
	Disfigurement	Theory	Model	Framework	
All Text	x	x			497
	x		x		598
	x			x	267
Title	x	x			0
	x		x		2
	x			x	0
Subject Terms	x	x			0
	x		x		0
	x			x	0
Type of Research and Words (after using the inclusion and exclusion criteria)					
	TI Title	TX All Text			
Keywords	Disfigurement	Theory			9
	Disfigurement	Model			4
	Disfigurement	Framework			1
Total of articles to analyse that fulfill the inclusion and exclusion criteria					14

Table 1 – Advanced Research following the Boolean method in the EBSCO, Web of Knowledge, PubMed and Web of Science databases

RESULTS

There's an increasing number of investigations that focus their study on facial disfigurement. In this systematic review, we used the EBSCO, Web of Knowledge, PubMed and Web of Science databases and obtained 80 articles that focus on disfigurement. From those, 49 focus their study on facial disfigurement. Only 14 approach disfigurement using a theoretical model or approach. The revised articles refer to qualitative studies.

Besides researching between 1960 and 2016, the first article published was in 1963 and the last in 2014. On table 2, we notice a big gap between 1963 and 1997 leading us to think that this theme is increasingly sought in the scientific Community.

For example, various studies have taken a cognitive approach to understand how a person adjusts psychologically to facial disfigurement. In this line, Kent (2000) defends that body exposure activates cognitive schemes on body image leading the individual to constantly take care of it. Later in 2004, Moss and Carr developed a study demonstrating adjustment to visible difference as a product of cognitive schemes. These cognitive schemes are based on past experiences, which organize and guide the information process of the self and that include individual social experiences. When analysing the subjective relation of

the seriousness and the adjustment to disfigurement, authors might differ in opinion, Moss (2005) refers that the greater the seriousness perceived, the worse is the adjustment; on the other hand, De Sousa (2010) defends the existence of various personality traits and other variables that contribute towards the quality of life and to the adjustment to facial trauma, compromising the quality of life of the individual and influencing the psychological adjustment to facial disfigurement.

Facial disfigurement could have social implications. A social approach allows for the understanding of the existence of beliefs and social behaviours that are disseminated by it and that influence the individual in the sense that a person avoids judgements by promoting irrational thoughts and beliefs. A person can also be the target of stigma or compassion of others (Rahzani et al., 2009), unleashing feelings of guilt and shame (Henry, 2011). In this way, individuals judge their appearance by the norms of their social context (Clarke et al., 2014), and if it results in a low level of social support, a person will be unhappy with one's appearance (Rumsey & Harcourt, 2005).

Studies focused on appearance defend that the interpersonal dimension is considered to be the biggest psychological challenge for most individuals with acquired facial disfigurement. Subjects have to deal with the social reaction to their facial appearance (De Sousa, 2010; Partridge, 2010).

Rumsey and Harcourt (2005) refer that, due to the complexity that the psycho-social impact has in the construction of the appearance of a person it is inappropriate to use only one or two theoretical methods to evaluate concerns with appearance.

Author(s)	Year	Analysis (Theory, Model, Frameworks)
Adsett	1963	Approaches the Psycho-analytical theory on the emotional reactions of cancer disfigured person.
Partridge (book chapter)	1997	Shows the SCARED model to describe feelings and behaviours of the subject showing visible differences and by those who know subjects who have visible differences.
Newell	1999	Shows the Fear-avoidance model on body image, referring a study that suggests a cognitive-behavioural approach as being useful in visible differences. The author mentions that the Avoidance model may be prorogued amongst subjects with facial disfigurement.
Dropkin	1999	Refers studies based on the Stress-coping model on individuals that had head or neck cancer surgery, they make a predictive model based on the adapting results achieved post-surgical.

<i>Clarke</i>	1999	Suggests in this study the Reach out model , characterized by eight principles or instruments, coded as an acronym that helps the subject to conceive different coping strategies. This author also has available a structure that offers psychological interventions for subjects with facial disfigurement.
<i>Kent</i>	2000	Shows a Psychological and social model as an explanation for the personal and social consequences of the visible face differences. Theory approaches centred on body image, social anxiety, social skills and social stigma may be used to understand the experiences of the subjects with disfigurement It appears to be likely that therapeutic approaches based on different models are useful because of these influences various types of adjustments to their visible differences.
<i>Moss and Carr</i>	2004	Whilst analysing the role of the concept of self in adjusting to disfigurement, they realised that the Cognitive-behaviour theory has been centred in possible changing factors.
<i>Maddern et al.</i>	2006	They defend the idea that knowledge of social skills model may help researchers and doctors who work in the disfigurement area, providing structures for social skills. These authors reinforce that in clinical practice the Cognitive-behaviour approach is considered to be a useful and beneficial strategy.
<i>Brill et al.</i>	2006	These authors refer that the Psycho-analytical theory dating back to the beginning of the twentieth century is focused in distorted body image and that the Cognitive-behaviour approach offers better evidence on the efficacy of interventions regarding the anguish experienced in the alteration of the body image. These authors defend that the perception processes such as attitudes are important for the understanding of the body image and that the Cognitive and behavioural approach has a more logical structure to exploit thoughts, feelings and behaviours associated to disfigurement. These authors propose a cognitive and behaviour structure for psychological management to be applied during the first year of post-surgery, suggesting objectives for therapy, potential problems and therapeutic methods.
<i>Edwards et al.</i>	2008	They refer that on subjects educated on the premises of the Cognitive-behaviour model it allowed a positive change in their behaviour when suffering from serious burns.
<i>Thombs et al.</i>	2008	As per the Partridge scheme , the first months after being burnt are characterized by a survival mode, having the main focus on physical recovery and rehabilitation.

<i>Tagkalakis and Demiri</i>	2009	<p>They mention that many confrontation and adaptation processes suggested by the Cognitive-behavioural model aspire to eliminate and reduce shame, as well as the fear that is associated with facial disfigurement.</p> <p>The Cognitive-behavioural model may be used as a scheme to explore the prevalence and the form of these difficulties and its efficacy in social interactions, including strategies for rehabilitation.</p>
<i>Rahzani et</i>	2009	<p>These authors use the Grounded theory to understand the reactions experienced by the subjects who have facial disfigurement caused by burns. The use of this theory is justified by the capture of social processes within social contexts.</p>
<i>Konradsen et al.</i>	2009	<p>They implement the Grounded theory to explore the nondisclosure of the disfigurement in interactions between patients and nurses during surgical treatments for facial cancer.</p> <p>These authors mention that the Fear and avoidance method explains how subjects deal with their disfigurement. Silence may be seen as a strategy to avoid dealing with the disfigurement.</p>
<i>Bonanno and Choi</i>	2010	<p>They use the Grounded theory to map social experiences of individuals with facial disfigurement resulting from cancer.</p>
<i>Bradbury</i>	2011	<p>The author mentions that in the Biomedical model there is a general assumption that those who suffer from severe disfigurement will suffer from higher levels of anxiety.</p> <p>They show a wide range of models and frameworks of the Cognitive-behaviour and Psychosocial interventions for anxiety due to visible differences.</p> <p>Detailed work is shown for the intervention of Cognitive-behavioural therapy on subjects with visible differences.</p> <p>Examples:</p> <ul style="list-style-type: none"> - Framework for interventions to promote psychosocial adjustment in the concern of appearance; - Models and frameworks to expand the conceptual approach to managing appearance-related distress; - Framework for clinical assessment.
<i>Clarke et al. (book)</i>	2014	<p>In a case study, the Cognitive-behaviour Therapy proved to be effective in the intervention of a young adult from Maputo-Mozambique with acquired facial disfigurement and a congenital “albino” issue.</p>
<i>Mendes (book chapter)</i>	2020	

Table 2 – Chronological main results for the Disfigurement Research (Theory, Model and Frameworks)

DISCUSSION

In a phenomenal perspective, the body is the base of the understanding of the human experience, and it can be seen as the basis of reasoning to understand the self (MacLachlan et al., 2012). The outstanding feature and the centrality of the face are a strong source of influence to be judged the attraction of by others, meaning that individuals with facial disfigurement normally experience negative and stereotyped reactions regarding their visible traits (Elks, 1990). A not so attractive visage can result in discrimination, may influence the choice of a profession and other situations. This can lead to low self-esteem and a poor quality of life (Bradbury, 2012; Soni et al., 2010) as the psychological impact of these high levels of dissatisfaction with the appearance affects self-perception and social function (Rumsey & Harcourt, 2012).

A single theory describing the understanding of the body image is unknown. We know that it will play a fundamental role in the quality of life of a person, throughout their lifespan, experiencing the influence of the body image in emotions, thoughts and behaviours (Cash & Pruzinsky, 2004).

Jackson (2004) defends that the face plays a primordial role because it is the source of social information, being more stable than the appearance of the rest of the body. This author postulates that facial attraction is generally classified by social attraction. (Callahan, 2005) defends that the face communicates pride and shame, the “type” of personality, hope, humour and love as well as it can also express disapproval, sadness, horror and apathy.

Research on the concern with appearance lets us understand the importance of the face in light of the communication of ideas, perceptions, communication and intensity of emotions, self-reflection, self-concept, self-esteem, amongst other expressions. Facial disfigurement shows strong psychological and social alterations in the life of the individual (Bradbury, 2012), influencing his body image, the quality of life and self-assurance, hindering social interactions (Rahzani et al., 2009). The adjustment to disfigurement is quite variable as it is also influenced by the media, society and culture (Alex Clarke et al., 2014) in which the subject is inserted, thus making difficult the use of a single theory for the understanding of the psychological adjustment related to facial disfigurement whether acquired or congenital.

Some researchers adapt structures from other contexts to understand the psycho-social impact of visible differences in the life of a person. Given the complex interaction between individual and social factors influencing the degree of visible differences perceived by the subject that could incapacitate them socially (Rumsey & Harcourt, 2004b). Despite its importance, those who are unhappy with their normal appearance reveal characteristics (emotions, thoughts, behaviours) that are identical to those who suffer from visible differences (Moss, 2005). Martin and Newell (2005) defend that facial disfigurement supports a high risk of psychological disturbances (with a particular incidence in high levels of anxiety and depression), and avoidance of social experiences due to their attempts at

hiding and refusing to expose themselves before others (Martin & Newell, 2005) is inherent to the associated inter-personal difficulties and shame (Moss & Carr, 2004).

Although those who have facial disfigurement can experience high levels of psychological stress, given a traumatic event that is aggravated by facial dysfunction in the case of acquired deformity and chronic pain (Islam et al., 2010), Moss (2005) defend that many of these people adapt to their altered facial appearance. Within this scope, the cognitive-behavioural approach has been very useful in its scientific production aiming at the understanding of the image of the body (Cash & Pruzinsky, 2004).

Table 2 shows that during the last few years various researchers are concerned with a person's appearance, these selected articles show the importance of various theories, models and frameworks in the evaluation and intervention of congenital and acquired facial disfigurement. The cognitive behavioural approach is the one that is most frequently used in quantitative research, including the grounded theories, those that are used in qualitative theories, intending to find theoretical explanations to social processes.

Although there are multiple overlaps amongst various types of approaches, each model renders a unique contribution towards the understanding of the adjustments to visible differences.

In conclusion, given the idiosyncrasy of the individual in their psychological adjustment caused by a visible facial difference, we conclude that the cognitive behavioural approach (as a theory, model and structure) is clearly dominant in evaluation and intervention processes for individuals with a visible difference. It is important to emphasize the importance of resorting to a model in these cases because the body image perception includes many variables. Although this article identifies a diversity of theories, models and frameworks, used during evaluation and intervention processes in individuals with facial disfigurement, each of them only contribute to the understanding of the adjustment process to their visible difference.

As for the limitations of this study, we noticed that this is an area of great concern among the scientific community but not always the results of treatments are published and accessible. Treatments for individuals with facial disfigurement aren't a new practice but lack consistency in their methodological approach. As each case needs a personalized view and adapted methodology we can only study patterns and not generalized plans that could fit all. As most treatments aren't published, we might not have a complete idea of the most beneficial treatments so this is an area that needs to continue being studied. Another limitation or challenge in this study is that the term disfigurement isn't well established in the scientific community leading to several side interpretations that in some cases could even be associated with a negative emotional feeling. Due to this problem, some authors are starting to use the term visible differences.

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