Chapter #6

PAIN, PATIENTS' NEEDS AND HEALTH-RELATED QUALITY OF LIFE

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ABSTRACT
Pain is a widely discussed phenomenon due to its complex comprehension and impact on satisfying life condition. It is related to physiological, psychological, spiritual and social aspects. Considering these dimensions, Cecily Saunders conceptualized "Total Pain", in an article written around 1965 (Saunders, 2006). Since the person cannot realize working activities, house's expenditure may enhance as total workforce decrease, especially if the patient is the provider. Isolation leads to suffering originated from feelings (guilt, rejection, fear, impotence, incomprehension), because there is a lack of relations and autonomy. It occurs by individual external and internal factors. As one cannot follow his/her social circle, there is a weakened relationship. Depending on the disease, there is social stigmatization on how pain is expressed and cultural environment presents negative prejudgment. Pain generates the need to reorganize/adapt to a new health condition, which does not always reflect the earlier lifestyle. Some measures can be taken to minimize suffering from those who live with significant impact on global quality of life. Receptiveness by professionals, family members and society can slow down those consequences. More efforts towards policies that promote a humanized treatment seems important to future's pain management.

Keywords: chronic pain, social adaptation, symbolic representation of pain, social practice.

1. INTRODUCTION

Pain is a phenomenon that exposes the person to adverse conditions in both collective and individual contexts. It presents correlations with many life scopes, influencing and being influenced by personal characteristics and mean of insertion. Due to negative interference in psychological and social dimensions, there may be suffering and relation with humor disorders, such as depression and anxiety (Camon, 2012; Marquez, 2011).

Regarding social matter, pain can cause significant impact in patient's support network. Depending on the level of pain and experienced circumstances there may be limitations to the person through the reduction of spare time in psychosocial sphere and life style maintenance. Consequently, losses are from practical order (financial dimensions, routine organization and adaptation) or associated to the subjective (social relationship investment, perception of the lived experience) (Camon, 2012; Chapman & Gravin, 1999).

Pain phenomenon also interferes in the ones who live with the person's suffering. There is a tendency in becoming responsible for psychosocial support, defined as:

> "a scale of care and support which influences both the individual and the social environment in which people live and ranges from care and support offered by caregivers, family members, friends, neighbors, teachers, health workers, and community members on a daily basis but also extends to care and support offered by specialized psychological and social services." (UNHCR, 2009).

Thus it is offered by the individual's support network, usually constituted by familiars. Obligatory support interferes in family structures, once it becomes unstable and needs to recover the balance through the reorganization of occupational roles to supply economic, operational, logistic and social demand. Besides that, family takes care of primary needs and pain treatment, even without being prepared, which can amplify pain to social circle (Lewandowski, Morris, Draucker & Risko, 2007; Metha & Chan, 2008).

Social representation of pain is one of the pillars that characterize social pain. Diseases and social stigmas create discomfort and exclusion for the one who is living certain situations. It raises feelings like anger, repulsiveness, fear, pity, desire of distance from both sides, which leads to a conflictive relationship. In consequence, there is quality decrease of affective bond and relationships consuming.

Considering this background, the present chapter discourses about the interfaces of pain correlated to social dimensions and subjective consequences on the individual's social life.

1.1. Pain

The International Association for the Study of Pain (IASP, 2012) defines this term as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". It is multifactorial and counts with sensorial, physiological, cognitive, affective, behavioral and spiritual components. Subjective elements (underlined ones) will influence on how pain stimulus are transmitted (World Health Organization, 2012).

Another classification system is by pain length: acute and chronic. When it is acute, pain presents short duration and appears immediately after a lesion that justifies this feeling. Chronic pain manifests for a longer period and can be associated to a specific illness. This condition is harmful to quality of life through continuous compromising and temporality of pain effect. The other two categories are less emphasized because they refer to etiology and anatomic location (WHO, 2012; Currie, Stone & Durham, 2015).

According to the World Health Organization (2012), pain can be analyzed by four aspects. There are physiological mechanisms classified as nociceptive (when there is specific pain receptors activation), or neuropathic (when Central Nervous System or Peripheric is affected). Also, there is mist pain, in which nociceptive and neuropathic pain co-exist (Werhagen & Borg, 2010; WHO, 2012).

1.2. Subjectivity & pain

When comparing emotional to sensorial experience, pain definition points to the phenomenon subjective relevance. Emotional factor is related to perception, an element built through experiences and representations formed and stored in mnemonic register.

In spite of representational activity being individual, it is directly related to collective context, once it happens in the person's relation with the external world, influenced by cultural conception. It is apprehended and then an internal world is constructed with particular meanings (Jovchelovitch, 1995).

Thereby, social representations are present in society and defined, according to Moscovici, cited in Walmsley (2004), as a "system of values, ideas, and practices that establish a consensual order among phenomena" and "enable communication to take place among the members of a community by providing them with a code for social exchange" (p. 3).

Pre-established definition is interpreted and modified following the way each social group perceives the phenomenon and its value. Regarding pain, social representation is

related to the way pain is exposed, reason, local, gender, previous experiences lived by that group. If a certain community perceives that those who are in pain will soon become sick and decease, then symbolic representation may be that pain is related to death that is why it can exacerbate pain sensation by the collective association with the term death.

In those circumstances, each individual's symbolical pain activity will be associated to perception consciousness and symbolic representation of pain, considering the group's social insertion.

1.3. Total Pain

The terminology was conceived by the physician and writer Dame Cicely Mary Saunders (1918-2005), who asserted that pain embraces physical, psychological, spiritual and social aspects. This definition was created from Saunder's care for terminal patients, in which she noticed suffering was arranged by those components (Camon, 2012; Didwaniya, Tanco, Cruz & Bruera, 2015; Metha & Chan, 2008).

At first, Total Pain was only used to describe terminal patient's perceived sensation; however, the experience of pain does not depend on the disease stage because Total Pain components are present in the entire process, from de etiology until its resolution.

If the individual complains and seeks aid, it is commonly referred to physical pain stimulated by organic causes and perceived in the body (Capelas, 2008; Santos, 2009). It is usually the starter to other types of pain, so the control of physical symptom is prioritized in medical pain treatments. Nowadays, there are studies that search physical pain understanding dissociated to others, in order to help the treatment of those who do not have conditions to express more elaborated feelings, such as children or people with cognitive impairment.

Psychological pain desolates the individual when psychic suffering is presented due to life conditions. It can be broken out by many reasons: impotence towards the discovery of a serious illness, loss of the healthy body (Capelas, 2008; Santos, 2009). Suffering interferes in emotional state and the way to perceive and react in diverse situations. Some people face pain by focusing on the problem itself; others on the emotions and sometimes, no coping leads to suicide attempt. This is not about the desire of death; whoever suffers with pain does not want to continue living in the actual condition. When humor is altered, pain can be intensified and depression can manifest. A simultaneous treatment for both comorbidities is necessary to obtain effective results (Holmes, Christells & Arnold , 2012; Ohayon, 2004; Trivedi, 2004).

Spiritual pain is connected to the meaning an individual gives to existence and balance of life. It has strong influence in religious beliefs, once religions often bring conceptions about origin and appropriate behavior among life and expectations after death (Capelas, 2008; Santos, 2009). Studies show relevance in religious interference and spiritual techniques usage, like meditation to improve physical and mental quality of life (Beiranvand, Noparast, Eslamizade & Saeedikia 2014; Siddall, Lovell & MacLeod, 2015).

Finally, social pain refers to the individual's experienced pain considering the group's social and cultural mean of insertion (Capelas, 2008; Santos, 2009).

1.3.1. Social Pain

Social aspects permeate the entire individual's pain process. There is prejudice in self-world relation and the conflicts of internal (the individual with himself) and external order (individual and social mean) can occur by different involved subjectivities, leading to distinct forms of the phenomenon comprehension.

This understanding can be amplified through quality analysis of social context because of the possibility to present personal or collective risk factor if the condition is unhealthy. For example: working setting provokes emotional and mental fatigue to the employees (difficulty in cognitive functions), besides well-being prejudice (Erick & Smith, 2014; Oberlinner, Yong, Nasterlack, Pluto & Lang, 2015).

Pain can also appear as suffering when its perception is associated to social ruptures caused by separations or alterations in human relationships (Eisenberger, 2012b; MacDonald, 2009; Spears, Lea & Postmes, 2001).

Social pain can be related to health impairment resulting from physical symptoms and diagnosis with reserved prognosis or in palliative care, because such adversities cause suffering and social economical damage that affect personal relationships and social status.

Feelings like rejection, exclusion and isolation in these situations can be understood as an interface between social and psychological pain. Researches in this area already confirm these feelings cause similar physical pain sensations through experienced suffering intensity (Eisenberger, 2012a; Eisenberger, 2012b; Sissa Medialab, 2014).

The present chapter explores the conception of social pain associated to health, mainly physical. We are going to discourse about social pain lived as consequences and connections with other symptoms.

In order to help content comprehension and also exemplify extracts, we will use preliminary results of a research about Quality of Life, Anxiety and Depression in patients with chronic pain assisted in a Chemotherapy Ambulatory. The sample had 52 patients with oncological clinic, who claimed to be in pain for over a month with parameters above 4 in Visual Analog Scale (VAS). 79% (n=41) were women and the mean age was 54,8 years old.

It is important to emphasize that Total Pain is an intertwined multidimensional composition. So, the contribution of interdisciplinary intervention and integrative approach of the person in pain are essential.

2. BACKGROUND

Social pain is characterized by external and internal factors. The extrinsic ones are difficulties came from social context and deficits in the involved people relational quality process; intrinsic factors are the psychic functioning aspects that influence in the relationship with the external mean.

Among external factors of pain, there is social economical prejudice due to the impossibility to exercise labor activity and financial burden proportioned by treatment (Camon, 2012).

These mechanisms are influenced by the context and other social group interests. In diseases and clinical symptoms, social representations vary according to the scientific knowledge acquired from causes and consequences, affected population, contamination risk. Some illnesses are permeated by negative stigmas that become difficult to demystify, such as Acquired Immunodeficiency Syndrome (AIDS). Thus, it is viable to reduce carrier's prejudice and increase the effectiveness of health education by professionals and society in general (Arraes, Palos, Barbosa, Teles, Souza & Matos, 2013; Dantas, Abrão, Freitas & Oliveira, 2014; Joffe, 1995).

Work is an essential function for identity formation and social role played by the individual, once the person tends to be recognized by the job done. Damage in this sphere can generate identity crisis, loss of value towards social mean, and, consequently, suffering. Working setting allows social relationships and is where the individual tends to concentrate

most of the time. The absence of this environment may represent significative restriction in social circle (Hogg & Terry, 2001; Haslam, Knippenber, Platow & Ellemers, 2003; Dutton, Roberts & Bednar, 2010). Moreover, it is common that the person has an identification with the profession and the anchored social roll of the labor activity because the individual recognizes and (Ashforth & Humphrey, 1993; Dutton, Roberts & Bednar, 2010).

Financial burden is also an element to the individual's sufferance because it is related to social. Either by the loss of income sources or treatment costs, the lack of financial resources allows fewer accesses to material goods and to places that could proportion comfort and well-being.

Despite the fact that significant pain is related to financial matter, studies point out that social support network has higher value than acquisitive power (Zhou & Gao, 2008). One of social pain's approach can manifest when the individual is not able to keep social relationships due to health conditions. The person perceives as a prisoner of his/her own body, so it is difficult to maintain social bonds, independently of the emotional state. Studies show there is increasing risk of death when the patient's social relationships are quantitatively and qualitatively decreased (Cacioppo & Cacioppo, 2014; Cohen, 2004).

As the main support network is family, the research realized in a Chemotherapy Ambulatory showed that 62% presented familiar caregivers. Familiar support and their help in treatment is substantial to both practical and emotional terms, once the patient is not always able to realize self-care and neither gets motivated to persevere in treatment without closest people's support. Such statement corroborates with other studies in the area with diseases and specific symptoms (Bacigalupe & Plocha, 2015; Takai, Yamamoto-Mitani, Abe & Suzuki, M, 2014).

Many patients from the oncological study revealed their main discomfort was the hard work and preoccupation brought to their family, mainly to the caregiver. Therefore, social pain has to be considered in familiar conjunct because it is complementary to the patient's experienced pain. Usually, family members also live significant losses in routine social role, so they can provide care and necessary support for the patient. Omnipotence feeling related to the beloved's pain can also cause sufferance to the family (Liu, Kim & Zarit 2014; Ovayolu, Ovayolu, Aytaç, Serçe & Sevinc, 2014).

Another extrinsic factor of social pain is gender. The research in a Chemotherapy Ambulatory showed a higher number of women who complain about pain in a higher and more diffuse intensity. It can be associated by many biopsychosocial variables, finances and social role representation (Vieira, Garcia, Silva, Araújo, Jansen & Bertrand, 2012). It infers that men's role in contemporary society is more connected to family's financial maintenance and restrict access to personal emotions. Thus, there may be resistance in expressing pain and difficulties in contact suffering propitiated by this sensation.

There are the intrinsic factors associated to internal aspects of the individual's psychological and emotional issues. In face of extended time exposed to a repulsive stimulus like pain, the person can get discouraged and have negative thoughts and feelings, such as sadness and anguish (Camon, 2012). The way each one deals with the situation will be according to the psychic functioning, coping, risk and protective factors (Bussing, Ostermann, Neugebauer & Heusser, 2010; Kranz, Bollinger & Nilges, 2009; Linton & Shaw, 2011).

One of the internal resources used as self defense mechanism is social isolation. Social contact becomes extremely difficult for the patient, so it is preferable to be alone for a long time. This behavior is justified: if the individual feels to be bothering or a burden for the family; not feeling comfortable to share his sensations; to feel inappropriate or rejected by the insertion group.

Sufferance occasioned by social isolation is related to the insertion context and not only being as an individual and correspond to an impact motivator (Dahlberg & Krug, 2006). A study realized with neurochemistry for pain relief from social exclusion did not present results. This suggests the hypothesis that this kind of pain is not only associated to physical aspects (Miller, Bourrasseau, Williams & Molet, 2014).

Isolation is directly related to morbidity and mortality indexes, including suicide (Cacioppo, Hawkley, Norman, & Berntson, 2011; Gaillardou & Matusevich, 2014). It is an attempt of self-aggression, in which the individual searches for his/her own death. It is connected to diverse factors, to the history of psychic functioning, and experienced suffering, either momentary or extended. Especially in chronic pain, there is an eminent suicide risk, as a trial to escape from that unpleasant sensation and to leave an uncomfortable and permanent life situation (Hooley, Franklin & Nock, 2014; Pompili, Lester, Leenaars, Tatarelli & Girardi, 2008).

3. FUTURE RESEARCH DIRECTIONS

According to the exposed, there are two subjective aspects wherein social pain is contemplated, both social and individual. Each of these perspectives has its value and influence in suffering generated to the one who is in pain and to the environment components. Further researches can study comprehension and intervention to minimize the impact of social pain.

These professionals are responsible for understanding this complexity and also not letting to be imprisoned in a single line. Reflection allows the malleability needed to Men's social insertion and the construction of complex processes that integrate and make us capable to rebind and restore complex processes that integrate and recompose the comprehension of experience and allows the possibility of emotional elaboration.

4. CONCLUSION/DISCUSSION

For a better comprehension of a social phenomenon, such as pain, it is important to verify a group's values, the manner an individual symbolizes psychic resources to deal with the situation. As a result, is it necessary to understand social and symbolic representation of pain.

Social representation is related to the theory a group creates about someone or something. According to Moscovici, one of the pioneers of Social Representation Theory, there are two main mechanisms in social representation: anchoring and objectifying. The second is when an abstract concept acquires a concrete form, what is in thought is transferred to a physical form. Anchoring is present when a new concept is classified according to a familiar context for a certain social group (Moscovici & Duveen, 2000).

With respect to pain, there are variables that interfere in its social representation, as the social group, etiology, place, consequences of pain in an individual's life. In the conducted study realized with oncological patients there were statements of discomfort and embarrassment to talk about pain outside the hospital environment because it can be perceived as 'foolishness' or 'tiredness'. Thus, there is stigmatization and disqualification of this feeling by other people; and empathy turns out to be. Researches show that even between health professionals, there are different interpretations of patient's pain (Narayan, 2010; Nencini, Sarrica, Cancian & Contarello, 2014).

This condition of constitute and simultaneously being constituted by social and cultural context is allowed because the individual is body mass and also a psychic being.

What we feel, think and perceive form our subjectivity. Social psychology has an important part in this process that contains real and symbolic. Men's incompleteness still guides unending researches (Kruglanski & Higgins, 2007).

An individual's perception is relevant in sickness and its symptoms. It will be one of the parameters for emotional balance, an important aspect to accept clinical conditions and to help cure process. Social and individual are complementary, so it also maintains emotional balance for both support network and patient (Makris, Melhado, Hamann, Walke, Gill & Fraenkel, 2014; Péoc'H, 2012; Pinto, Mclntyre, Nogueira-Silva, Almeida & Araújo-Soares, 2012).

The embracement by professionals, social center and society in which the patient and his family are inserted, can help in the reduction of consequences caused by pain and disease. However, social explanation about the phenomenon and the investment in humanizing policies in treatment are necessary, so there is mobilization that allows control and pain management. Therefore, opportunities amplify the improvement on Quality of Life and rescue the autonomy of the constituent and constituted individual's social environment.

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