

## ETHICAL CONSIDERATION AND PSYCHOSOCIAL CARE FOR PEOPLE WITH HEMOPHILIA

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### ABSTRACT

Psychosocial support is an important part of comprehensive care for people with hemophilia. Beyond the medical condition, individuals with hemophilia commonly face a number of psychosocial challenges. Social workers, psychologists and counsellors play a key role in helping new patients and their families adapt and learn to cope with their new reality.

It is possible to have hemophilia and still live a full life, even for those who face many social and economic challenges. Medical treatment alone does not automatically translate into better quality of life. Beyond medical treatment, the responsibilities of the hemophilia treatment centre include educating families about how to manage hemophilia and helping them find interventions for psychosocial issues.

**Keywords:** hemophilia, psychosocial care

### INTRODUCTION

The concept of psychosocial phenomenon defines the result of collaboration, approaching and merging the psychological with the social, representing a new level of reality that for which other qualitative determinations are defining.

The most expressive form of social connection with the psychological is the behavior, being carried out with the participation of consciousness but without being fully included in the categories of consciousness; it refers to "the totality of the reactions which a living being expresses in an organized manner against the excitements included in the Environmental factors; it is established, every time, based on a choice (selection) from a set of possible reactions, completed choice for maintaining optimal form and functions of that being as a whole". (1)

The components involved are of intellectual, structural, intentional and emotional nature in a closed, stereotyped manner or open and capable of improvement. Alfred Adler says that "being human is not only a way of speaking, but being a part of a

whole, to feel part of a whole". (2) The formation of the human personality is the result of a complex process of socialization, in which personal, environmental and cultural factors interact.

The quality of interpersonal relations can be estimated through more subjective indicators, with a critical impact in any family prediction: socio-emotional climate; sexual wellbeing; the authenticity and completeness of communication between partners and their children; keeping a dynamic balance between merger and psychological autonomy; the fluency intergenerational boundaries; coherence and consensus models of spousal and parental role offered to children in the process of education; the degree of comfort and security, resulting from the psychological feeling of family affiliation, as an antidote to loneliness and unbalancing abandonment; the capacity of storage and transmission of positive spiritual value patterns, psychosocial; mental and somatic health of family members. (3,4)

The numerous achievements obtained in over years of studies and researches have managed to solve many of the problems of hemophilia patients. The first and most significant achievement is ex-

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tending the life of these patients until not so long ago few reached maturity, they can now get a degree of autonomy and to integrate into the economic circuit, especially in developed countries. (5)

Decreased mortality has entailed other aspects: patients with chronic illness should face additional problems related to long-term survival in disease conditions and treatment administration, which generates a range of emotional reactions.

Hemophiliac patients have to complete periods of disability, they must endure lengthy treatments and they must cope with various experiences and feelings like fear and insecurity. The process of adapting to the disease is often difficult and can lead to dysfunctional psychological symptoms that may be associated with psychiatric morbidity over time, both for the patient and members of his family. In the case of children with chronic conditions, psychological complications risk is twice as high as in their healthy peers.

Fewer in number compared to other diseases, for solving their problems medical and auxiliary staff are trained from many different specialties. Hemophiliacs problems are worn for discussion, conferences and world congresses are organized which are held periodically in different countries since 1963. (6)

At the same time in many countries where the number of hemophiliacs is higher, hemophiliacs associations were established whose work is coordinated by the World Association of Hemophiliacs from Montreal and is affiliated with the World Health Organization.

The presence of hemophilia in the patient's life imposes upon him to face his whole life with the changes imposed on his body. This event can be devastating both from a physical and psychological standpoint and loads the patient with a series of losses that customizes this pathology: loss of independence; the changes of life style; uncertainties regarding the future; the feeling of helplessness; the separation of friends; changes in physical health; changes in body image.

The permanent disability which a hemophiliac body is subject to causes an alteration of psyche, with serious repercussions on the individual personality. Intense and permanent pain causes an increase in psychological tension and an internalization of personality, even more so, as the hemorrhagic accidents are more frequent and more intense. Changes in the patient's psyche appear in the early childhood. The suffering to which it is subjected causes him to lose his normal aggressiveness, characteristic to the age of childhood, inven-

tive spirit and his rich imagination. He shows a lack of trust toward himself, a decrease in spontaneity, shyness, refusing contact with his entourage, tending to separate from the other kids and to segregate in his own family, along with his referral doctor. (7,8)

The approach in the personal matters with special needs is a complex one, since it is recommended an increased attention to the use of description terms in order not to harm human dignity. Psychopedagogy uses several terms that, depending on how to address the problems of persons with special needs, can clarify a series of boundaries (9,10):

- medical and somatic aspects – deficiency;
- functional aspect – inability or disability;
- the social aspect – the handicap.

The three concepts have been proposed by the World Health Organization in order to give a unitary definition. (11,12) Next to the parameters organized on the three plans, the contextual factors are taking into account: personal and anmiental or environmental.

Based on these distinctions the international classification of Functioning, Disabilities, and health (ICF 2001) was elaborated, adopted as a working document by the O.M.S. ICF is a tool for achieving the rights of persons with disabilities, but also a useful method in standardizing health states, unification of diagnosis approaches and evaluation of health and functionality.

Hemophilia, especially in terms of inadequate treatment, may be a cause of disability. In the case of hemophiliac patients, compliance with a degree of disability shall be carried out in case of severe forms, depending on the intensity of specific functional disorders and self-service capacity, characterized by the need for care and supervision.

In recent years the treatment of hemophilia has made real and important progress. All undertaken research have aimed mainly at improving the quality of life for patients. At the same time, it is tried to find a treatment to cure the disease. (13,14,15)

At present, medical treatment is mainly done with factor VIII transfusions. This therapeutic method, due to transfusion, involves a number of risks as the transmission of HIV/AIDS and hepatitis viruses.

Prophylactic treatment of hemophilia A is aimed at transforming a severe form in one that is medium or mild, thus avoiding possible complications, sequelaes and invalidity. Depending on the duration of the treatment, the prophylaxis may be short or long, and after the moment of administration, primary or secondary prophylaxis.

The optimum age of primary prophylactic therapy is around the age of 1-2 years before the occurrence of hemorrhagic accidents of the child. The treatment is followed until the late teens or even more, being effective in protecting the joints of children with a severe form of the disease [idem].

Secondary prophylaxis is indicated after repeated bleeding episodes, especially after the appearance of consecutive haemarthroses in the same articulation. Secondary prophylaxis is recommended for children who did not attend a primary prophylaxis in their childhood. (16,17)

At the same time, through helpful psychological treatment it is tried to maintain or improve the level of compliance to the medication through a consideration of some of the factors (social, psychosocial, mentally, biological).

Methods of psychological treatment that can be applied to the hemophiliac patient, that are complementary to the medication treatment are numerous and have effective results. Their roles are multiple, but they can never replace the medical treatment that the patient follows. (13)

Interventions for hemophiliac patients may include cognitive-behavioral approach or interpersonal approach, which has the effect of reducing depression. Cognitive reconstruction can reduce the state of helplessness or the negative ideas, while assertiveness and support training for the self-efficacy of the patients can help the patient cope with the symptoms of the disease better. Psychosocial intervention has good results in terms of improving on an emotional level, including also quality of life improvements. Furthermore, psychotherapeutic interventions for stress management are useful in hemophiliac patients in order to reduce depression, stress and also increases the protective factors as social support.

Studies have shown the importance and involvement of cognitive behavioral therapy in adherence to treatment. (18) The therapeutic alliance is not considered a causal variable in adherence to treatment, but a mediator variable. This shows that therapy itself directs adherence to treatment, follow-up treatment which eventually directs favors positive outcomes as keeping in check the symptoms, such as in the case of hemophiliac patients. At the same time, therapy may be an important predictor for the

results of the treatment of patients with more severe disorders of psychological nature.

In relation to the psychological treatment of the hemophiliac patient, understanding the disease, the acceptance of a new life style and the search for meanings of the illness are the first steps to improve the quality of life. (13,19,20)

The hemophilia diagnosis, realized, in terms of direct impact in changing health status and assumed, in terms of identification and acceptance of the therapeutic protocol for the patient representation becomes a new life style. The patient tries to adapt, to change its behavior and attitudes in relation to the general aspects of his life and the people with whom he relates. The disease becomes the determining factor of the actions, measures and individual perceptions. In a psychological plan, depending on the structure of personality, the patient may develop conditions such as anxiety disorders, panic attacks, depression, obsessive behavior and at the same time, the disease is seen as a stressing factor that leads to major changes in the individual's life. (21)

For these reasons it is important to consult a specialist in the field to determine the type of intervention/psychological support and the appropriate psychotherapeutic protocol. In order to reduce the severity of the symptoms and consequences by modifying aspects of life, a therapeutic program will be established which shall be communicated to the patient.

## CONCLUSION

People with bleeding disorders live everywhere around the world. Health professionals at hemophilia centres play an important and at times critical role in patients' lives, imparting key tools to help them improve their lives and actively participate in the treatment and management of their hemophilia, and ultimately lead interesting and productive lives.

Hemophilia and other chronic illnesses affect each person beyond the physical problems the condition can cause. In order to optimize their efforts to facilitate the health of their patients, it is important for treatment centres to provide psychosocial care as part of an integrated multidisciplinary approach.

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