

# PATIENT'S EXPLANATORY MODEL OF DISEASE AND ITS INFLUENCE ON CONSERVATIVE TREATMENT OF DIABETIC FOOT

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Social and medical anthropology studies make a distinction between two explanatory models of relating to disease for which, in the English language, two different terms are used: "illness" and "disease". If "illness" represents the patient's model, based on his personal beliefs and perceptions, "disease" is the medical model which is the base of the treatment. There are researches showing that education programs used in the treatment of diabetes generally have only short term results, one of the reasons being that they do not take into account the patient's model of relating to disease. This model may have a favoring or inhibitory role in the treatment, the importance of its investigation being emphasized in the recent work of specialists. Based on the literature in this field, the aims of the paper are to investigate a series of individual beliefs and perceptions which can contribute to the development of the patient's explanatory model of relating to disease, with an important role in the evolution of conservative treatment of diabetic foot.

*Key words:* Foot; Diabetes; Conservative treatment; Design; Education; Patient's model.

## INTRODUCTION

Diabetic foot is one of the biggest challenges of diabetes, in which foot ulcers are common complications of the peripheral diabetic neuropathy. 30–50% of patients with diabetes have diabetic peripheral neuropathy, while it is estimated that approximately 15% of patients with diabetic peripheral neuropathy will develop foot ulcers in their lives<sup>1</sup>. In the most advanced cases, the evolution of complications arising from foot ulcers leads to different levels of limb amputations with dramatic consequences, both economic and emotional for the patients' lives. Approximately 3% of all patients with diabetes have leg amputations at various levels, mostly as a result of unhealed ulcerations of the foot<sup>2</sup>. In Romania there are approximately 700 000 diagnosed diabetes cases and 300 000 undiagnosed cases. Around 90% are type 2 diabetes. Over 50 000 new cases per year are registered while the WHO estimate a total

of 1.395 million people with diabetes in Romania in 2030<sup>3</sup>. In Bucharest, about 5% of all new consultations are represented by foot ulcers<sup>4</sup>. Mechanisms of foot ulcer development, having diabetic peripheral neuropathy as main risk factor, can be based on conditions which could be:

– extrinsic to the foot – such as local trauma due to loss or diminishing of the sensory capacity – or,

– intrinsic to the foot – such as the development of the structural deformations of the osseous system or muscle imbalances, having the appearance of high pressure areas as consequence<sup>5–7</sup>.

The conservative treatments which include the use of therapeutic or custom-made footwear and accommodative foot orthoses play a special role in the activities of prevention and treatment of foot ulcerations. Their primary mode of action is given by the accommodative principle which implies redistributing pressure from high pressure areas to adjacent areas<sup>8</sup>. Efficacy of conservative treatment

is measured through parameters like: developing rate of ulcers, duration of their healing, callosity development or recurrence rate, while secondary measurements include patient comfort and satisfaction, measuring quality of life or financial considerations of the treatment<sup>9</sup>. Vileikyte<sup>10</sup> shows that, although neuropathic foot ulcers should be prevented by controlling risk factors, in reality, with some exceptions, the occurrence rate of ulcers or number of amputations does not decrease. It is considered that the prevention process does not take sufficiently into account other risk factors such as psychological, behavioral or socio-cultural factors. A significant number of research reveals that diabetic neuropathy can lead to ulcerations not only due to physical factors – such as injuries or structural deformations which generate high pressure areas – but also because of additional ways of socio-cultural nature, whose determining factor is the way in which the patient builds his own explanatory model of the disease<sup>11-13</sup>.

Even if both quality of life assessment using generic instruments [general, non-specialized in a specific disease or body part, for example: the foot] and specific educational programs for patients with diabetes, prove a decrease of short-term risk of ulcer development, there is a low level of evidence in favor of long-term positive results<sup>11,13,14</sup>. In addition, generic instruments for assessing the quality of life and educational programs are focused toward developing personal care skills, without investigating how the patient understands diabetic peripheral neuropathy and its consequences and complications or the emotional reaction generated by the disease. Basically, what Kleinman defines as the “patient’s model” related to the disease is not investigated<sup>11</sup>.

Studies of medical anthropology agree that there are three levels of socio-cultural behavior, described as / 15 /:

- what patients declare they do,
- what patients are seen to do,
- the beliefs and personal perceptions system that guide patient behavior.

Within this context, the success of conservative treatment of diabetic neuropathy requires the existence of such components used in understanding how lifestyle, beliefs, attitudes and personal perceptions related to the disease, and social context [family claims...] could influence the positive or negative evolution of treatment.

## PERCEPTIONS AND BELIEFS RELATED TO FOOT AND FOOTWEAR AS ELEMENTS OF THE PATIENT’S MODEL

In a reference article, Kleinman<sup>11</sup>, distinguish between terms that define the “sickness”, according to the perception of each part involved in the medical act. Thus, if for the physician “sickness”, defined in English as “disease”, is an abnormality in the structure or function of the body, for the patient, the same concept, defined in English as “illness”, represents the subjective perception of disease. World Health Organisation [WHO] defines disease as a continuum of cause and effect, beginning with impairment, going to disability and ultimately leading to handicap<sup>16</sup>. According to Kleinmann, both concepts of “illness” and “disease” should not be viewed as separate entities but as explanatory models of a complex phenomenon called “sickness.” It should be noted that in Romanian language there is one correspondent word named “boala” used to translate the words “illness”, “disease” and “sickness”. Clinical cases are presented in the literature demonstrating that patients respond to peripheral diabetic neuropathy complications manifested in the foot by building their own different representations or models related to disease which are different from the medical models<sup>10</sup>. The patient’s explanatory models can adversely affect the evolution of treatment generally<sup>17</sup> and the conservative treatment, particularly. This paper further proposes an analysis of the main beliefs and perceptions related to foot as they are presented in the studied literature. According to Vileikyte<sup>10</sup>, individual beliefs or perceptions are represented both at an abstract level [name, evolution, outcome expectations related to disease evolution, etc.] and at a concrete level [symptoms, consequences of disease, etc.], each level having five characteristic areas:

- perceptions about the nature of the disease – what the disease is and how it manifests,
- expectations regarding the duration of disease,
- the consequences or the impact of the disease,
- the causes or antecedents that have led to the disease,
- control of disease, the perceptions and expectations related to the ability to control the disease.

A rich information source on perceptions related to the foot and footwear, both in socio-cultural and religious fields, is represented by the work of anthropologist researcher Margo de Mello<sup>18</sup>

in which she illustrates that perceptions related to cultural and religious beliefs foot revolves around the idea of purity or impurity. Thus, in Hindu and Muslim cultures, as feet touch the ground, considered dirty, removing the shoes at the entrance of halidoms symbolize the removal of impurity. The feet are seen as impure or dirty parts in many religions or cultural traditions in African or Asian countries, therefore to point the foot plantar surface towards another person is deemed unacceptable. Washing feet before prayer in Islam and Buddhism symbolizes a purification act, while in Christianity, washing the feet of another person is perceived as an act of teaching / learning of humility.

Many perceptions, positive or negative, related to footwear exist in different cultures. Footwear can have a significance of luck, because for a long time it was a product worn only by wealthy classes, who afforded their acquisition. In England, tying shoes to the back of the married couples' car symbolizes good luck, while in Romania the bride must put sugar in her shoes to please the groom<sup>19</sup>. At the wedding, the bride and groom try to step up each other's feet, because there is the faith that whoever is first stepped on the foot is the one who will obey the other<sup>20</sup>. Also, the left foot brings bad luck, while the right foot brings good luck. Due to the protective role of footwear, it is regarded as good luck if it is put in the walls of houses built in the countries of Europe and America.

Lately, researchers have paid special attention to illness related patterns created by patients with diabetes based on perceptions or personal beliefs. In a comparative study on the reaction of patients from different cultural regions on hearing the gestational diabetes diagnosis, Hjelm<sup>21,22</sup> notes that some patients are worried about their problems related to the complications that will occur within the foot, while for others, wearing therapeutic footwear for diabetes [assimilated with orthopedic footwear] is perceived as really demoralizing. This negative perception can cause a patient's model with an inhibitory effect on the treatment.

For the study of illness model in the patients with diabetes, Vileikyte and collaborators<sup>13</sup> have developed a questionnaire to investigate how patients perceive and interpret peripheral diabetic neuropathy, with the aim of identifying those representations that influence the personal self-care process. The questionnaire was built based on existing instruments for investigating the "illness" models of patients. To test the construct validity of

the new instrument a generic instrument called "The Revised Illness Perception Questionnaire" [IPQ-R] was used. The sample of subjects consisted of 495 patients with an established diagnosis of type 1 or type 2 diabetes and diabetic peripheral neuropathy. Development of the questionnaire highlights some of the key perceptions of patients needed to be investigated when the "illness" model of patient is considered important. According to the areas of manifestation of beliefs underlying the formation of a patient's model<sup>10</sup>, a series of perceptions characteristic to those areas considered representative is given. Thus, three important factors related to the perceptions about the nature of the illness were identified:

1. Good blood circulation means healthy feet:

– loss or reduction of sensation means poor blood circulation in the legs – this belief is in contradiction with studies<sup>5,6</sup>, which shows that peripheral vascular diseases by themselves are responsible for a small percentage of the total foot ulcerations caused by diabetes, arterial insufficiency having an inhibiting role in healing ulcerations];

– good circulation in the feet means that the patient will not have ulcers;

– if your feet are not cold when touched, it means they are healthy.

Having created a model based on these perceptions, a patient with diabetic peripheral neuropathy may decide to wear sandals, which expose the fingers to injury risk identified as a risk factor in the development of ulcerations<sup>7,6,10</sup>. This is contrary to medical model according to which the shoes have to confer protection against injuries.

2. correct interpretation of neuropathy:

– loss or reduction of sensation means problems with nerves in the foot;

– a loss or a reduction of sensation in the legs is possible, along with the experience of pain,

– it is possible to record a decrease in sensitivity, in parallel with existing touch sensation;

3. ulcers with pain:

– this implies the existence of a pain in the foot with ulcers;

– as the ulcer evolves, it will become more painful;

– an ulcer may be developed without feeling pain.

Two factors are identified related to the causes leading to illness:

– the physical causes of ulcers and

– the causes due to institutional care system.

The main perceptions related to the physical causes that lead to ulcers are: changes in the foot shape, inappropriate footwear, excessively developed callosities, dry skin.

Another important aspect is the control of ulcer evolution; there is the belief that diabetic foot ulcers require more time to develop. This perception may have an inhibitory effect on the conservative treatment. In a study on a sample of patients with diabetes presenting superficial foot ulcers, Armstrong and collaborators have prescribed a pressure redistributing device for the patients with the indication to wear it for a period of seven days continuously. The study shows that almost 75% of the daily steps have been taken without the device, which was contrary to medical indications<sup>23</sup>. Patient perception in this case was that the home [place where they live] is safe and may not present risk factors for emergence and development of ulcerations<sup>26</sup>. Also, the three levels of behavior described above<sup>15</sup> can explain the results of this study in that the system of personal beliefs and perceptions – patient's illness model – can determine the patient to act contrary to medical indications.

Another set of perceptions<sup>1</sup> that can help to build a patient's model with inhibitory effect on the treatment include those emotions related to:

- life environment: depression, low self-esteem, family role changes, how they are treated by friends and family, the feeling of physical and emotional dependence, etc.;

- the institutional environment in which the medical treatment takes place, manifested by the presence or absence of trust in medical staff.

In patients without a history of ulcers, a personal explanatory model regarding the diabetes can lead to less attention paid to self-care and daily check of foot, which is a risk factor for the ulcer's occurrence. Another important factor in the formation of negative perceptions is the recurrent ulcerations, generating negative beliefs and attitudes towards personal control over developments of possible complications in the feet or towards medical control<sup>10</sup>.

Another set of perceptions is closely linked to how self-image is affected by footwear design recommended for diabetes, this being common in women. Depending on the severity of deformations resulted from the evolution of diabetes, two types of footwear can be used:

- therapeutic, deep footwear: relatively normal-looking shoes, but with larger internal space due to

the technical requirements needed to introduce the accommodative foot orthoses with a role in redistributing pressure, and modified to accommodate the size of the foot<sup>8,24</sup>,

- custom-made or orthopedic footwear for advanced foot deformities. This is generally seen as an element in a series of negative perceptions formed over the subsequent development of diabetes<sup>21</sup>.

Perception of footwear as bad or ugly could be the cause of its poor acceptance, and in many cases cause a rejection, especially from women. Failure to accept or refuse therapeutic or orthopedic footwear may be correlated with aspects of their own identity or self body image<sup>25,26</sup>.

Illness, as perceived and experienced by the patient, is a determinant factor of his behavior, representing a socio-cultural phenomenon<sup>11</sup>. Neglecting personal explanatory model of disease can lead to a poor patient's adherence to its educational programs, and the formation of the inhibitory effect of perceptions over the conservative treatment of diabetic foot<sup>10,11</sup>. Counter-education made on the basis of popular beliefs [eg. folk remedies, healers], through secular people, or through other information channels such as media<sup>28</sup>, can be the basis for developing an explanatory patient's model with inhibitory effect on the conservative treatment. Generic tools developed for investigation of personal models related to illness or to investigate the quality of life are not sufficiently sensitive to capture particular aspects generated by a disease such as diabetes, imposing the development of specific tools for a disease<sup>1</sup>, or specific to a particular anatomical part, such as diabetic foot in the case of this article<sup>27</sup>.

## CONCLUSIONS

In the conservative treatment of the diabetic neuropathy, patients guide their behavior in relation to personal explanatory model of disease. This is based on individual perceptions over the nature, causes, duration, control capacity, consequences and impact of illness on personal life. Literature demonstrates the existence of a specific set of personal perceptions and beliefs related to peripheral diabetic neuropathy and correlated with diabetic foot and footwear. There are many tools developed in order to evaluate personal illness model of patients and the quality of life. Because the patient's personal explanatory

model may have an inhibitory effect on the evolution of conservative treatment, investigation of this model and assessment of life quality can help achieve positive results on the long term, correcting the short term efficiency of the educational programs and conservative treatment.

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