



ORIGINAL PAPER

The subjectivity of the illness-experience

MARIA LUISA FIGUEIRA

Full Professor of Psychiatry (Jubilated). Faculty of Medicine. University of Lisbon

Abstract: In the present paper we will explore the different levels of deregulation and expression of suffering induced by a somatic illness or by a disease in individual subjectivity. These levels are part of a singular functional and organizational structure of the self and personality.

Keywords: illness-experience, meaning of illness, subjective suffering

Introduction

To the strictly naturalistic view of diseases Barahona Fernandes opposed an understanding of the diseased man in his personal suffering, in what he calls the “*dolência*” a term impossible to translate in English. It means the wholeness of the singular suffering experience of each diseased man in his circumstance or situation¹. This same term was introduced in the sense used above in the Spanish language by Honório Delgado² to designate the state of mind associated with the awareness of a disease. Barahona Fernandes in Portugal then used this term of the vernacular Portuguese.

He stated: “not the disease but the Man diseased must be directly understood in his suffering – “*dolência*” – as it is experienced by the self in his way of being and in his life behaviour” (...) “bodily phenomena must be understood in this new perspective (anthropologic medicine or personalistic medicine) in close and intimate relationship with the psychic phenomena. The later, can also be tied with the spiritual processes – the intuition, the value and meaning that the patient confers to the suffering and to the medical situation, in facing the existential circumstances – the hope, the resignation, the anguish or despair...”.³

It is the distinction between the disease itself, the value and meaning that represents for the subject, by one side, and the emotions, feelings and the psychic attitudes as-

sumed by the self by the other. It’s the suffering that arises in the moment a man faces an unexpected and undesirable event that disturbs his well being that limits his freedom and threatens the natural course of his existence. It is also the need to change the expectations and to face the possibility of pain, invalidity and death. Suffering “is only a part of the totality of the experience of Man facing the disease”⁴.

Illness means much more to the patient than the experience of symptoms: “Is fundamental experienced as a global sense of disorder”⁵ that is a primary experience of loss of wholeness.

As Susan Sontag said:

*“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of the other place “.*⁶

Changes brought by illness are not equivalent to the harm produced by the disease in our organs or systems of the body. The whole person has to face an unpleasant and unexpected event (disease) that carries not only body sensations and feelings by which the person knows to be unwell (illness), but also a threaten to the course of its existence, to its expectations and freedom.

Illness is experienced as a “global sense of disorder”⁶ that includes: an awareness of body disruption, pain or impairment; a sense of loss of body integrity; a loss or reduction of control and a loss of freedom

Above all, the individual illness experience is full of present or future suffering and ultimately of the near incapacity and death. Illness is a new identity, a new way of living

Address

Faculty of Medicine of Lisbon. University of Lisbon

Address: Av. Prof. Egas Moniz

Postal Code 1649-028 Lisbon

Country: Portugal

Telephone: + 351937247900

Email: marialuisafigueira@gmail.com

and of being. An individual trip made to the dark side of life, with or without return.

Illness experience is singular and subjective. Every person suffers in its own manner, but shares with others a common and symbolic meaning of some particular diseases. The social meaning of disease is part of the personal suffering. Nevertheless, it's a complexity of experiences that undermines the position of the individual facing a new disease. Cultural values are part of the circumstances of the living experience.

In the model of personality developed by Barahona Fernandes, it is the personality in its complexity and in its situation in the world that a disease globally disturbs. Illness is characterized by feelings of unhealthiness, body disruption, pain or impairment and for the purpose of understanding the variety of these expressions we must consider several components of the Personality structure or organization (Table 1 – A Model of Personality).

Pre-reflexive awareness of the body and Vital feelings of suffering

Our own body primal experience is a pre-reflexive sensory body experiencing first occurring at an immediate level (basic self) in which it is still not present a separated body awareness from the reflexive and narrative self.

For instance when a body changes occurs at this level it is not the localized feeling of pain but either the diffuse painful experience included in the whole body awareness. Nevertheless, Zutt⁷ says that the subsequent body awareness is already in itself a reflexive attitude on the whole body experience

For Lopez Ibor⁸ the experience of our body existence is not a sum of sensations but either a global unitary experience. The wholeness of this experience arises from the bodily sensations named *vital feelings* (*Vitalgefühle*).

Harald Höffding⁹ first used this expression referring to the vital sensation as a specific feature of kinaesthesia, whose components are not specifically located within the body and have less intense quality when compared to other sensations types. They are merely elements of a global feeling of our existence in its wholeness that are generally designated as vital feelings.

The different bodily systems, either circulatory, endocrine, respiratory, digestive, muscle-skeletal, exert their influence on this feeling in a global manner. The apparent link between the different vital sensations merge together thus originating a peculiar vital form. Already Leibnitz in its letter to his theologian friend Antoine Arnauld, wrote *“It is true that we do not distinctly perceive all the movements in our body, as for example the movement of the lymph, but to use an example which I have already employed, it is somewhat in the same way that I must have some perception of the motion*

of every wave upon the shore so that I may perceive what results from the whole; that is to say, that great sound which is heard near the sea. In the same way we feel also some indistinct result from all the movements which go on within us, but, being accustomed to this internal motion, we perceive it clearly and noticeably only when there is a considerable change, as at the beginning of an illness. It is to be desired that physicians should apply themselves to distinguish more exactly these kinds of confused feeling which we have within our bodies”.¹⁰

Vitality for Ortega Y Gasset has a uniqueness character and allows us to feel life itself both in health and disease¹. Vital feelings can be lasting and can have a certain intentional nature- they in themselves indicators of the vital values. They signal and announce in a primitive and pre reflexive way, either a threat or a pleasant occurrence. Vital feelings are spontaneous and apparently emerge without the self-implication or self-reflexivity.

For instance vital anguish, vital sadness or vital fatigue appears independent of external events, are unmotivated and depending mainly on the state of the Self.

*“I am not comfortable or uncomfortable rather I feel myself comfortable or uncomfortable with all my body up to the last cell”*⁸ (Lopes Ibor)

It is in this individual *“myself”* that the vital feelings express the body awareness.

Guy de Maupassant expresses these feelings in his text *“La Horla”*

May 12 *“Whence do these mysterious influences come, which change our happiness into discouragement, and our self-confidence into diffidence? One might almost say that the air, the invisible air, is full of unknowable Forces, whose mysterious presence we have to endure. I wake up in the best spirits, with an inclination to sing in my throat. Why? I go down by the side of the water, and suddenly, after walking a short distance, I return home, wretched, as if some misfortune were a waiting me there. Why? Is it a cold shiver which, passing over my skin, has upset my nerves and given me low spirits? Is it the form of the clouds, or the colour of the sky, or the colour of the surrounding objects which is so changeable, which have troubled my thoughts as they passed before my eyes? Who can tell? Everything that surrounds us, everything that we see without looking at it, everything that we touch without knowing it, everything that we handle without feeling it, all that we meet without clearly distinguishing it, has a rapid, surprising and inexplicable effect upon us and upon our organs, and through them on our ideas and on our heart itself”*.¹¹

The body is the only part of the world that is simultaneously felt from within and at the same time perceived in its surface. The body is an object for me and I am the body itself. Nevertheless, there is an indissoluble link between the feeling of the physical body and how the body as an

object is perceived. The former are feelings of my body state and the later bodily sensations whereby a conscious object builds itself up for me. Quoting Jaspers “Awareness of our body’s existence, normally an unnoticed neutral background for consciousness (...) may undergo a number of exceptional changes as a whole (...) states of anxiety in overcoming pain may deeply involve the body, absorbing men in annihilation or in strength.”¹²

Awareness of the physical state of our body is phenomenological related to the ground of our experience of the body as a whole. The distance we establish of our body feelings in relation to the awareness of the self or the extent we feel our oneness is quite variable. In the extreme range we can feel our pains as something distant from ourselves and our body as an alien object of medical observation. We can also feel the changes of our body state as an unexplained experience for our self-awareness and threat for our own body.

*“It was especially during this experience of convalescence that I felt physically confused. Just the short distance to the bathroom seemed like a major project for which I had to plan and get ready. I began to watch my body for strange signs of pain and disquieting irregular symptoms. You see, the odd thing is that, while taking my walks, I became very aware of my pulse and circulatory system. I was very conscious of my heart beating very fast, much too fast. After I walked down some steps in the hospital my heart would just take off and then not seem to know how to settle down once I took a rest. It was quite an alarming sensation, as if my body had become alien to me. I needed someone to understand this, to reassure me, to explain what was happening to me and get me in proper touch with my body, but nobody seemed to know how I felt and what I was going through”.*¹³

Physical sickness is a vital affective state that can be a prodromal of organic illnesses. It is an unpleasant and vague feeling preceding the pain and localized sensations—the loss of the sensation of well being that is present in the states of health. To Honório Delgado, the sickness penetrates deeply roots an intensification of the awareness of the body as its own reality². The body assumes a privileged meaning in the conscience and the exterior world is suffers an undervaluation “proportional to the overvaluation of the body”. There is a lowering in the vital tonus, the affects fade and the interest in the external reality decreases.

At a basic level of our personality, illness can be an experience of awareness of our vital sensations, of painful changes on our body sensations, and of disruption of our lived body. Our body becomes *an object* to us and to the others. The ill body is transformed into a diseased body.

Reflexive experience of threat and anticipation

As it is clear not everyone experiences in the same fashion the appearance of an illness and has different ways of be-

ing ill. The idea of a disease takes particular aspects with great individual variability but it is associated almost of the times with negative characteristics, events with unpleasant tonalities, threatening evolutions.

The threat is implied in the state of the absence of health. The antinomy health/disease is one of the ontological categories of the thought. Life in its stream is threatened by an interruption—the anguish comes from the diagnose uncertainty and the suspension or detour from the project of existence. New meanings may arise and origin reorganizations at the level of conception of the man’s position in his world and in relation with other person’s world. It is in the subjectivity level and values that the idea of the disease changes the feelings and creates singular experiences of each human being. For whom experiences, the illness it is something vague that even labelled only assumes a denotative value that expresses itself in a sickness manifested in a determined cultural shape.

If for the doctor the label is associated with a pathogeny for the patient the label is a metaphor. There are illnesses with a very well known pathogeny but don’t exhibit symptoms. These illnesses if not complicated don’t imply suffering. On the other hand there are «silent» illnesses which diagnose is made in an extremely advanced phase. These diseases bare a symbolic burden of such suffering and lethality (cancer) that the diagnostic awareness is a brutal shock. Other illnesses bare incapacity in the medium term (Parkinson) that threatens all the existence Project. There are still diseases that imply the contagion and attain interpersonal relationships with its load of potential distance from the others. In these cases it is the world of intersubjectivity that is threatened.

The feelings inherent to the *dolência*, the condition of being ill, of feeling ill and the attitudes of the self in the presence of the illness rely on several factors: 1) external to the individual and his subjectivity (the acute or chronic features of the illness, its preconceived or predicted lethality); 2) intrinsic of the sick person: his cultural level and socio-economic status, the age, his biography, his way of existence. When someone confronts an acute illness of a trivial or common nature or even a predicable solution, generally starts an intense and quick fight towards the resolution of the situation. The cultural level and socio-economic status shape the way of experience the illness sometimes emphasizing the negative expectations by the value given to the situation.

The influence of the age in the value given to the illness is a consequence of the individual particularities - psychological and biographic. The illness during childhood especially if it has chronic features assumes relational relevance and changes the affective exchanges. It may induce attitudes of affective compensation and influence the future relationship with the individuals’ body. In adolescence the experience of timeless, strength, excessive con-

confidence in his strengths the immeasurable beliefs in the future, the optimistic coloration of the attitudes facing the fragility may favour the underestimation of the disease and the meaning of its evolution (prospective meaning). Later in the middle period of life or senescence the surprise facing the possibility of becoming ill might be less. Still others cultural factors related to the current cultural period influence the acceptance of the illness. The experience of resignation and the acceptance of the treatment without questioning are replaced by an attitude of fight for health, active search of information and participation in the treatment.

According to Honório Delgado the feelings that more frequently constitute “the subjective feelings by excellence of the diseases”², mainly the somatic ones are the physical sickness, the pain, the fear, the anguish. This group of reactions may be vividly elaborated in the shape of an anticipation of the threat to the project of existence of the individual.

*May 16. I am ill, decidedly! I was so well last month! I am feverish, horribly feverish, or rather I am in a state of feverish enervation, which makes my mind suffer as much as my body. I have without ceasing that horrible sensation of some danger threatening me, that apprehension of some coming misfortune or of approaching death, that presentiment which is, no doubt, an attack of some illness which is still unknown, which germinates in the flesh and in the blood.*¹¹

Pain induces several psychic reactions that express themselves through several behaviours and bodily attitudes that rely on the individual sensitivity. It is an affective sensorial state originated by different physical situations that resound upon the psychic life of the individual in his whole, causing frequently opposite feelings –from intolerance and despair to resigned acceptance or serene stoicism. Pain can be the first sign that something is not well in the body nevertheless it is phenomenological different from suffering. Frequently the knowledge of the cause of the pain if associated with a benign situation, not threatening to life, might decrease the suffering connected to it. This is what happens in very painful situations that can be integrated in a positive comprehensible situation.

Not knowing the origin of the pain and its cause may increase the suffering associated with the pain itself. The pain can be experienced as an uncontrollable situation, which increases also the suffering attached to it. The meaning that the individual gives to the feeling of pain it is an important dimension of the suffering.

The individual expresses his or her pain in a variety of forms. Some persons try to elicit the compassion of others and are very expressive and demanding; others assume almost an heroic position and deny themselves the overt expressing of suffering; still others deny the link between pain and suffering and felt the former as not be-

longing to the own body. Its very difficult or even impossible to fully understand the real dimension of others pain. There is a kind of expansive tension of the pain² (Honório Delgado), initially localized, extends its influence to the wholeness of psychic life, and at the same time is an appeal to the others. Von Weizsäcker spoke of a “community of pain”, in the sense that pain is an appeal for helping the sufferer and builds a human relationship founded in the efficacy of our palliative impulse.¹⁴

Anguish or fear. Affective state caused by the eminence of a danger, it is awakened by the disease and the perspective of death that the existence of the individual faces. The meaning gained by the disease relies upon preceding illness experiences (personally experienced or through the experience of others) personal susceptibility and temperamental disposition. Anguish is predominantly diffuse, invasive, and without a defined object and manifested motive. It is a more vital feeling than fear but has a similar expression in the bodily level. Erwin Straus states (1) (cit. por Honório Delgado - *Erwin Straus: Geschehnis und Erlebnis, Berlin, 1930*) - “each man has his natural place between security and the centre of the threat, he can not change it voluntarily”. The external circumstances change this place and bring it near to the pole of the centre of the threat then the anguish begins. Paul Ricœur states: “au plus bas degré, au niveau vital, l’angoisse concerne la vie et la mort; plus exactement, elle détecte la proximité de la mort par rapport à la vie. Cette proximité est une relation qui flotte entre l’extérieur et l’intérieur (nous aurons souvent à revenir sur l’ambiguïté de la menace total qui tout à la fois fonce sur nous et surgit comme du centre de nous-même)”¹⁵.

The psychic anguish is associated with the meaning of the disease in the relationship between life and death. Death is an external threat in the sense that life doesn’t imply death. - “absolument parlant, la vie pourrait être immortelle”¹⁵. The anguish brings near this abstract knowledge of ourselves in such a way that “death seems nurtured by life”¹⁵. It is extraordinary the description of Rainer Maria Rilke about this kind of anguish:

(1) Erwin Straus (1891-1975) German born neurologist, psychiatrist, and philosopher, was a member of the inner circle of the European movement of anthropological and phenomenological psychiatry “...the consciousness of the individual person unfolds as the experience of his own inner history. Every single moment is a phase in his historical becoming. Everything coming into consciousness in a specific moment is determined by how it fits into the course of this becoming or how it arrests or runs counter to it. Everything attention lays hold of, is present and is now. But this Now is the Now of the inner life-history, whose progress in becoming is not measurable by the standard of objective time.”

“And then, as I listened to the hot, flaccid stuttering on the other side of the partition, then for the first time in many, many years it was there again. That which had struck into me my first profound terror, when as a child I lay ill with fever: the Big Thing. Yes, that was what I had always called it, when they all stood around my bed and felt my pulse and asked me what had frightened me: the Big Thing. And when they got the doctor and he came and spoke to me, I begged him only to make the Big Thing go away, nothing else mattered. But he was like the rest. He could not take it away, though I was so small then and might so easily have been helped. And now it was there again. Later it had simply stayed away; it had not come back even on nights when I had fever; but now it was there, although I had no fever. Now it was there. Now it grew out of me like a tumor, like a second head, and was a part of me, though it could not belong to me at all, because it was so big. It was there like a huge, dead beast that had once, when it was still alive, been my hand or my arm. And my blood flowed both through me and through it, as if through one and the same body. And my heart had to make a great effort to drive the blood into the Big Thing; there was hardly enough blood. And the blood entered the Big Thing unwillingly and came back sick and tainted. But the Big Thing swelled and grew over my face like a warm bluish boil and grew over my mouth, and already the shadow of its edge lay upon my remaining eye.”¹⁶

Sadness like the anguish overcomes the vital level and becomes motivated. It is a form of suffering in the face of the perceived consequences of the disease, mainly if it changes the situational position of the person. Sadness means the helplessness in the presence of an irreversible course of a disease, the despair motivated by the loss of autonomy and the impossibility of projecting the future.

Meaning and diagnosis of the disease.

A threat for the integrity of the whole person is experienced with pain and suffering before the knowledge of the diagnostic of a particular disease. And it is the wholeness of the person that must be understood. Before the diagnosis the “disease” was experienced as an undefined distress at a vital level or a reflective painful experience of a body malfunctioning. According to Cassel¹⁷ the patient assigns a meaning to these feelings at the pre-reflective level of interpreting the sensations as a bodily distress but also at the cognitive level of giving identification to the disease. In the first level the individual feels the unfolding of something wrong and “alarming”, an undefined “presence”, he feels himself as “suffering from an illness”, in the second level he possesses an interpretation, he assigns a name, identifies “a disease that he suffers”. The vital feelings expressed as “I do not feel well, my balance is disturbed ... my body is malfunctioning...” are substi-

tuted by the perception of having a “disease”, a specific form of unhealthy body. The sick person experiences his body not anymore as the subject of a suffered illness, but as an object (a “being-for-others”, Tombs). The diffuse and spread distress acquires a meaning and is fulfilled with feelings that can range from the relief to the extreme anguish and despair.

This point is powerfully illustrated in the book of Kenzaburo Ôe – “The silent cry”. The character day after day awake with a diffuse and deep pain in his body. Then after a night in which he faint in the yard for some time, going then to bed, in the moment of awakening he felt:

“I was shivering continuously and suddenly come the fever. All my body was in a deep pain, but I also felt an acute and severe painful sensation in my hand. I realize that unconsciousness I was trying to scratch the land to make my own grave. The tremors and the deep pain become intolerable, and feeling my body disintegrated, and feeling the pain in each part of it separately I understood the meaning of my daily awakening”¹⁸

The meaning of the disease is determined by several factors. Previous experiences of illness conduct to a re-experience and actualization of past personal feelings and circumstances; the shared knowledge of “the other”, of the illness experiences by significant persons is another factor. The person is part of the cultural and social environment, shares with others the appreciation of the sickness experience, the meaning of symptoms, its negative qualities, the severity and lethality of the disease and its possible outcomes. The disease has also a personal meaning for each individual according to its life project and life circumstances.

Knowledge of the diagnosis

What happens in the moment the diagnosis is communicated to the patient?

I will illustrate the above assumptions with the description of my own experience of working during 5 years with patients in the moment and in the subsequently months (6 months) after the diagnosis of HIV infection¹⁹.

Data shows that some of them are able to psychologically adjust themselves to the social and psychological impact derived from the diagnosis of HIV+

Following the initial shock accounting with the network of social, community and friends support some are able to reorganize their way of living, and in this subgroup one doesn't found a higher prevalence of psychiatric disturbances when compared with the general population.

However other subjects are unable to achieve this state. Becoming aware of their HIV + condition is experienced as devastating and unovercoming event. Quite often they exhibit a range of psychopathological reactions and deviant behaviours dependent from some personality factors and social environment.

Acute reactions to the emotional shock following the diagnosis might significantly interfere with their emotional and cognitive functioning. For instance, these reactions might interfere with the subject's ability to comply with a set of decisions and recommendations regarding potential therapeutic interventions as well as directions towards preserving health through life style changes. On the other side, the degree of emotional disturbance might be so intense that it interferes with the subject's attention and full understanding of the amount of information being provided by the health caregivers.

Most frequent psychopathological reactions to the diagnosis are acute anxious or depressive adjustment reactions involving several emotional discharge modalities.

We will briefly review each of the main reactions found among these patients keeping in mind that a reaction pattern might emerge either isolated or associated with several other patterns.

(a) Catastrophic experiences followed by intense anguish, hopelessness and both vegetative and bodily anxiety with agitation signs, sometimes with psychic and somatic panic. This pattern is usual in subjects with a great insight and knowledge of either the disease in itself, or in those who have had a close relative or friend with the same diagnosis; (b) Acute depressive state with intense feelings of guilt, experiences of untreatable outcome and suicidal ideation; (c) Feelings of rage with overt aggressive behaviour directed against either the inefficacy of the medical therapeutic measures, social exclusion or health politics in broader terms. In close relation with this rage, might occur feelings of unfairness in close relation with the question "Why me?"; (d) Denial and disbelief regarding the diagnosis validity and degree of certainty especially towards the serum tests. This compensatory reaction tends to be brief and short lived.

At a narrative level of the self experience these emotional reactions might be associated with a group of concerns and worries mainly expressed by: doubts regarding how to become infected; immediate consequences on everyday life; prognosis both in short and longer term; fear of being socially connected with high risk groups like gays or lesbians, drug addicts etc.; fears of rejection and hostility by relatives, friends and social community in general terms; fear of being fired thus becoming unemployed; fear of becoming physically disabled or handicapped; fears involving loss of autonomy: guilt and ambivalence feelings towards his or hers sexual preference.

In conclusion: Subjects with an HIV + diagnosis probably go through a whole set of different individual experiences evolving the loss of an actual life environment (health, friends, expectations towards future) and the replacement for an acute uncertain future on which their only certainty is a shorter life expectancy.

As we mainly deal with young people, this profound change in their existence is probably experienced with intense anguish and pronounced accepting difficulties.

Awareness of impending death

For Cicero the whole life of the philosopher is a preparation for death: "The despise of death is an essential condition to free the soul of the fear of dying (magna videbatur mortis effecta contemptio, quae non minimum valet ad animum metu liberandum)"²⁰.

"All pain must be bearable" (dolorem que omnem esse tolerabilem) and "the resistance to pain is a mark of courage, nobility of the soul, capacity to support everything, to triumph over contingency". (virorum esse fortium et magnanimorum et patientium et humana vincuntium toleranter dolorem pati; nec vero quisquam fuit qui eum qui ita pateretur non laudandum putaret.)²⁰

The individual has a particular relationship with his own death never comparable with the experience of the others death.

Quoting Jaspers it is an experience completely incommunicable, totally secret, in a complete loneliness inside each man that "cannot be communicable to the self" but also to the others.²¹

It is a different relation of the one with the time-limited life of others; situation lived as a non-being of the other and at the same time as a continuity of our own being

The representation of our own death does not exist, it is "unthinkable", it's a relation that cannot be fully experienced.

Individually, man facing death assumes an attitude purely personal and may try to overcome it as a limit situation, but also may deny it with representations of a reversal meaning of an immortality idea.

Jaspers doubts of the possibility of doing an analysis purely intellectual of the death.

Since man is incapable of conceiving his own end (as his own beginning) his fundamental experiences of a world that is empirically "given" to him, are the experiences of time and transitoriness. Death contains in itself the elements of life. As it is known since Epicuro - Since death for myself can only be conceived only because I am alive, should I be death life does not have a meaning in itself.

An interesting clinical study of psychic changes during agony was made by Hans Rudi Bühler in Winterthur and published in the book "Acute syndromes in Somatic Diseases"²²

The author H.R. Bühler studied 15 patients in „agonic state“ defined as the moment after which there was a worsening of the psychical state of the patient and the moment of death could be anticipated. He observed each patient and the family during a mean time of 5 weeks with interviews and descriptive psychopathologic obser-

vations. The psychic changes in agony observed were a withdrawal and a loss of interest and motivation for human relationships, some patients display states of depression or dysphoria, and another's several psychotic syndromes: euphoric states, delusional ideas of persecution and hypochondriacs with some cloudiness of consciousness; and finally four patients had an inhibition of thought, poverty of thinking, in alternation with emotional hyperesthesia with self reference ideas.

During the last days of agony it was observed that the psychotic changes occurred in a dynamic way: in the first period meaning a fight against death and an increase of vital energy; in the second phase with an extreme anguish to maintain an attitude of strength and confident on future; in the third phase a great experiential diversity to maintain the refusal or on contrary the acceptance of death.

It was observed that the experiences of denial or acceptance of death did not presuppose a refusal of the believe that it will be a hope of an improvement or even a cure; the acceptance of death was never experienced as an enemy of life but as a freedom from suffering. For half of the patients the doubts expressed the refusal of death. All these elaboration of agony experiences was modulated by the personality of each patient)

Bühler penetrates only partially in these patients near death experiences. This is the mystery and limits of our possibility to understand what is non-experienced in ourselves.

Is the literature that can illuminate some of our experiences on suffering and death? The text of Herman Broch is an accurate description of the preparation for death and the intimate relationship between life and death.

*"He was listening to dying; it could not be anything else. The awareness of this had come over him without any fear, at most with the peculiar clarity which usual accompanies a mounting fever. And now, lying and listening in the darkness, he understood his life, and he understood how much it had been a constant hearkening to the unfolding of death; live unfolded, consciousness unfolded, unfold the seed of death - implanted in every life from the beginning and determined it - giving it a double and triple meaning, each one developed from the other, each one being the image of the other and its reality - was not this the dream-force of all images, particularly those who gave direction to every life?"*²³

The possibility of our own death can also be a rational experience, the acceptance of the inevitable and natural end. It is questionable if this is a defensive attitude or corresponds to a supreme conception of our biological nature. Why not every man assumes the position of Julius Caesar? May his path towards death is not through the illness experience, but through the struggle for power.

CAESAR

*Cowards die many times before their deaths;
The valiant never taste of death but once.
Of all the wonders that I yet have heard
It seems to me most strange that men should fear;
Seeing that death, a necessary end,
Will come when it will come
William Shakespeare, Julies Caesar
Act II, Scene II²⁴*

References:

- 1 - Gasset OY. *Ni vitalismo ni racionalismo*. Revista de Occidente 1924; Vol 2 (16):1.
- 2 - Delgado H. *Curso de Psiquiatria*. Barcelona, Editorial Científico-Médica, 1969.
- 3 - Fernandes HB. *No Signo de Hipócrates*. Lisboa, Livraria Luso-Espanhola, 1969.
- 4 - Fernandes HB. *Antropociências da Psiquiatria e da Saúde Mental (obras completas)*. Lisboa, Fundação Calouste Gulbenkian, 1998
- 5 - Toombs SK. *The Meaning of illness*. Dordrecht, Kluwer Academic Publishers, 1993.
- 6 - Sontag S. *Illness as Metaphor*. Middlesex, Penguin Books, 1977.
- 7 - Zutt J. *Psiquiatria Antropológica*. Madrid, Editorial Gredos, 1974.
- 8 - Ibor JLL. *La Angustia Vital*. Madrid, Editorial Paz Montalvo, 1950.
- 9 - Höffding H. *Outlines of Psychology*. Londres, Macmillan, 1891.
- 10 - Leibniz. *Correspondencia con Arnaud*. Buenos Aires, Losada, 2005.
- 11 - Maupassant Gd. *Le Horla*. Paris, Ollendorff, 1887.
- 12 - Jaspers K. *General Psychopathology*. Manchester, Manchester University Press, 1963.
- 13 - Van Manen M. *Modalities of body experience in illness and health*. *Qualitative Health Research: An International, Interdisciplinary Journal*, Sage Periodicals Press 1988; Vol 8(1):7-24
- 14 - Viktor von Weizsäcker. *Escritos de Antropologia Médica*. Buenos Aires, Libros de Zorzal, 2009.
- 15 - Ricouer P. *Temps et récit*. Paris, Seuil, 1983.
- 16 - Rilke RM. *The Notebooks of Malte Laurids Brigge*. New York, W.W. Norton & Company, 1949.
- 17 - Cassell EJ. *The nature of suffering*. New York, Oxford University Press, 1991.
- 18 - Oé K. *The Silent Cry*. Tokyo, New York, Kodansha International Ltd, 1967.
- 19 - Figueira ML. *Aspectos psicológicos e Psiquiátricos da Infecção pelo Virus da Imunodeficiência Adquirida*. Lisboa, Faculdade de Medicina de Lisboa, 1990.
- 20 - Cicéron. *Devant La Souffrance - Tusculanes II*. Paris, Arléa, 1996.

- 21 - Jaspers K. Psicología de las concepciones del mundo. Madrid, Editorial Gredos, 1967.
- 22 - Bleuler M, Willi J, Bühler HR. Akute Psychische Begleiterscheinungen körperlicher Krankheiten. Stuttgart, Geor Thieme Verlag, 1966.
- 23 - Broch H. The Death of Virgil. New York, Pantheon Books, 1945.
- 24 - Shakespeare W. Julius Caesar. London, Arden Shakespeare, 1998.