

Perception of Losses Experienced by the Diabetic Patient

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Abstract

A person living with diabetes mellitus is conscious that this pathology will not cause its death in the short term, but they face losses and experience grief on multiple occasions along with the chronicity of the disease. In most cases, the partner or close relative also experiences a great impact since they become a family caregiver. The goal of this study was: to analyze the perception of losses experienced by the diabetic patient along with the chronicity of the illness. **Method:** This was qualitative research, with a phenomenological method under the philosophical view of Husserl and the theoretical support of Kübler-Ross with a descriptive design. Four diabetic patients aged 18 to 75 years old of both genders participated; they asked for hospital attention due to complications of the disease. Selection of participants was by convenience up to reach saturation. Data were collected through semi-structured interviews, field notes and observation. The setting of the first contact was in a third-level hospital in Mexico City; the second one was through programmed home visits. These occurred by a chronogram agreed upon by the participants, and a room was selected with conditions of privacy to conduct the interviews; respect was always observed. Participants signed informed consent. Data analysis was according to Miles and Huberman, by means of three tasks: information acquisition, data transcription and codification, and conclusions. **Results:** After the qualitative analysis four categories emerged, as well as sub-categories, as follows: **Category 1:** Self-losses perceived by the patient, sub-categories 1.1 Beginning the mourn step: Negation; 1.2 Silent illness that produces severe damage; 1.3 Complicated/chronic mourn. **Category 2:** Emotions along the disease chronicity, sub-categories 2.1 Negation of emotions/distortion of natural emotions; 2.2 Decisions taken based on feelings. **Category 3:** Changes in the diabetic patient's nutrition, sub-categories 3.1 Culture: positive reinforcement from childhood; 3.2 Constant mourn; 3.3

Pleasure by forbidden foods. **Category 4:** Benefits in the diabetic patient, sub-categories 4.1 Need to be in a support net; 4.2 Bonding ties and love by relatives. **Conclusion:** Self, relational, material, and extensive losses that add to the diabetes mellitus chronicity accompany the patient with long-term negative emotions, but to accomplish the goals of care and limit the damage nourish its positive emotions; the starting point is from the perception of the first news knowing the diagnostic, if this reality is accompanied by thanatology counsel to diminish the negation and anger steps, when realizing the change in health, then a positive perception for this first mourn and more to come along time, will appear in the patient. Thanatology or health counsel will favor the patient to undertake illness control to have a better life quality.

Keywords

Diabetes, Patient Physical and Emotional Losses, Thanatology

1. Introduction

The diabetes mellitus type 2 (DT2) prevalence in Latin America is 8.88%, and it is projected to be 13.5% by 2040 [1]. Mexico is the country with the highest prevalence in the region with 16.9%, according to the International Diabetes Federation and the World Bank [2] [3]. The Mexican National Institute for Statistics and Geography (INEGI) accounted for 74,418 deaths in the first half of 2021 due to DT2 [4]. A person living with DT2 realizes that this pathology is not deadly in the short term, but they face multiple losses and mourns a long time with the disease before reaching the end for this or another cause. Among losses are the radical changes in social and familial roles, since the person becomes a patient in a public health institution, and at home from being a husband/wife, father/mother, etc., is now a dependent person without autonomy, and this leads to a full family restructuration. It is important to mention that in most cases, the partner or close relative of the patient also experiences a shock when knowing the diagnostic since tentatively it will lead to full disability or even death and it becomes the caregiver; this situation carries a change in the role and an overwhelm of losses.

Back in 1999, the World Health Organization (WHO) conceptualized the primary caregiver as a person that attends to the physical and emotional needs of an ill person; this role is assumed, in general, by the wife/husband, son/daughter, a relative or a close friend of the patient. It is a person that, even though is not a member of the institutional health team, neither to be aware of, has the maximal responsibility in the care and attention in the dependent or disabled patient's home [5]. Its attention is centered on prevention as well as on having better control, treatment and prognosis. DT2 that physiologically starts as premature aging could develop devastating complications in patients and generate an important socioeconomic impact with a high cost, both personal and social not only in treatment but also in the loss of productive years in the life of the patient

and the family caregiver [2] [4]. Then, the aim of this research was to analyze the perception of losses experienced by the diabetic patient along with the chronicity of the illness.

2. Methods

This was qualitative research focused on phenomenology under the philosophical view of Husserl, the Gestalt psychology in thanatology, and the theoretical support of Kübler-Ross with a descriptive design [6] [7] [8].

2.1. Inclusion Criteria

Four diabetic patients aged 18 to 75 years old of both genders participated, they asked for hospital attention due to complications of the disease, and they were helped by a family caregiver. Selection of participants was by convenience up to reach saturation.

2.2. Data Collection

Data were collected through semi-structured interviews, field notes and observation. The setting of the first contact was in a third-level hospital in Mexico City, which allowed the patient and family to be invited to participate in the research; the second contact was through programmed home visits. These occurred by a chronogram agreed by the participants, and a room was selected with conditions of privacy to conduct the interviews, respect was always observed. At all times, the responsible of the attention area facilitated the progression of the study. Participants signed informed consent.

2.3. Data Analysis

Qualitative data analysis allowed maintaining the original language of participants, as well as questioning about their experienced situation and their expectancies. Data analysis was according to Miles and Huberman, by means of three tasks: information acquisition, data transcription, and codification, and then the conclusions [9].

2.4. Ethics and Legal Aspects

For this research, the ethical issues were considered to ensure the validity of the work, with diverse sources: Ethical principles of the declaration of Helsinki [10], point number 6 that says, "Always must respect the rights of persons to safeguard their integrity. All precautions needed to intimacy respect of persons and to minimize the impact of the research on their physical, mental and personality integrity must be observed". To reach those goals confidentiality, the secrets exposed by the informants must not be revealed, and the recordings must be confidentially used only for this research, and along it limits persons imposed on information must not be exceeded, giving them complete liberty to withdraw.

The Belmont Report [11] clause B, essential ethical principles, considering re-

spect for persons, benefit and justice; as well as clause C, writing the informed consent, a document that contains the required elements such as information, comprehension, and willingness; in addition, to evaluate risks and benefits explaining that no risk exists for this investigation.

3. Results

Integration and interpretation of data obtained from the diabetic participants were obtained. After the qualitative analysis four categories emerged, as well as sub-categories, as observed in **Table 1**.

4. Discussion

Kübler-Ross was the first to publish an approximation to the death process, being an important descriptor of mourn enumerated in several steps [12]; later on, Kübler-Ross described that day-to-day losses are continuous, some of less impact than others [13]. Even without a clear identification of what happened, the person experiences much mourning along their life story, from the shocking news of being ill up to the death of a loved one [14] [15]; and how the affected person experiences their mourn, that is different for the accompanying persons. The steps had evolved from the moment they were presented up to claim that there is no reaction to the loss, neither that a typical loss exists. Mourn is so proper to life and individual as the person. According to Tizón [16], self-personal losses dealt with individuality and the body [13] [14], *i.e.*, the losses of intellectual or physical abilities, as it is shown in the speeches that made **Category 1**. Self-losses perceived by the patient, sub-category 1.1 Beginning the mourn step: Negation.

[] *I think I am still in negation, since to tell the truth I do not follow the specific diabetics' diet; but here a mental fight starts. I feel very fat and that fat had been accumulated, I have no teeth, I cannot see well at night, and even though I do not go to the physician. I keep my control and measure glycemia. E4.*

Table 1. Categories and sub-categories that emerged from diabetic patients.

Categories	Sub-categories
1) Self-losses perceived by the patient	1.1) Beginning the mourn step: Negation 1.2) Silent illness that produces severe damage 1.3) Complicated/chronic mourn
2) Emotions along the disease chronicity	2.1) Negation of emotions/distortion of natural emotions 2.2) Decisions taken based on feelings
3) Changes in the diabetic patient's nutrition	3.1) Culture: positive reinforcement from childhood 3.2) Constant mourn 3.3) Pleasure by forbidden foods
4) Benefits in the diabetic patient	4.1) Need to be in a support net 4.2) Bonding ties and love by relatives

To be able to identify the losses and process them, it is necessary that the patient identify those as a loss, which will lead to the mourning stage with its collateral psychological, emotional, and physical effects. In this regard, Kübler-Ross mentioned that the mourning process manifests with the initial negation, which acts as a buffer after unexpected and impressive news, and allows recovery of the person and with time to develop other protective measures [12]. During this step, beliefs that underestimate or maximize its complications may appear both due to ignorance of the disease or to its care, which lead to fear or vulnerability answers; however, the negation need exists in all persons at some point, mostly at the beginning of a disease then perception is being modified.

The diagnosis of a chronic disease has complex psychological and social consequences. Its disclosure challenges the patient-health professional relationship, regarding information or the knowledge the person has about the disease and the bond between users and health professionals. Disease perception is much more than the physical disability; the derangement could be unnoticeable at the beginning, as shown in the next speech: sub-category 1.2 Silent illness that produces severe damage:

[] *It is a silent disease such that you neglect it, as I did at the beginning when I knew nothing about diabetes. My sight was impaired and my teeth were the worse; as a person, I thought it was a normal disease, did not know that it caused so much harm even though I knew about the symptoms but considered them normal. When a physician told me you are diabetic, my first pre-diabetic, I did not feel bad since I knew to have all symptoms of diabetics. E4.*

Chronic disease is directly related to pain and death meanings that will modify life styles, habits, economy since no awareness of the applicable adjustments is made due to the lack of visible impairment, favoring the silent damage.

According to the International Diabetes Federation (2021), there are 537 million persons living with DT2 worldwide, warning of the public health problem; in Mexico, 16.9% of the adult population has DT2 as well as 30% of children [2] [3] [17]. The disease is unnoticed for many years, and being chronic the symptoms will manifest when the disease is already advanced [2]. When starting the therapy to control the illness symptoms, patients experience their absence or unreality leading to underestimating the middle term consequences on health, having no self-care behavior, which influenced the onset of the complications. According to Kübler-Ross when the denial phase is no longer maintained, it is substituted by anger, rage, uneasiness and bitterness, and by the continuous question, why me? [8], which are shown in the following speech, sub-category 1.3 Complicated/chronic mourn:

[] *A fellow partner asked me what was wrong. I answered her I was diagnosed as diabetic and I was very sad, like depressive, did not want to eat and got worse in my throat. That night I had to work and in truth it was very wearisome, many situations in the job, in my mood, because I asked myself: why my parents inherited this disease from me, my father, my mother, I will self-care as much as I*

can. E2.

The complicated mourn is defined as the lack of satisfaction of lived experiences, such that the person is overwhelmed and appeals to maladaptive coping behaviors [14] [18].

According to Tizón the complicated mourn meant qualitative, quantitative or temporal difficulties for processing, but not necessarily for a pathological build up [16].

Expression and experienced emotions are determined by the culture a person is immersed in; however, these could be different in each culture modeling behaviors and reactions when facing situations like the stress due to a mourning process. So, it will depend on the context in which the loss occurred, in this case, health, considering the bonds related to the loss, *i.e.*, the physical, the psychological and the emotional; as shown in **Category 2**: Emotions along the disease chronicity, and sub-category 2.1 Negation of emotions/distortion of natural emotions and 2.2 Decisions taken based on feelings. The findings agreed theoretically with Kübler-Ross, where she sustains that emotions shift when facing a critical situation, such as a mourning process, dissociating among self-compassion, bad mood, and mortification that do not help to take proper decisions [12], as shown in the next speech:

[] *I know I am sick, no need to repeat me that all the time, but I can do better things without bothering me. I am good at several things, and do not understand why the loss of my teeth happened to me, I have good oral hygiene. At job I cannot make a lot of effort, they know my background and cannot force me, otherwise I run to the physician's office.* E3.

According to Vigotsky an emotion is the integration of psychological processes, internal and external, shaped during the life story of the individual mediated by social influence, and tied with cognitive and affective aspects culturally associated [19]. It results from the assessment of the individual with its surroundings, as a product of experienced critical moments where equilibrium is distorted, and it acts as need status from accumulated individual experiences. As observed in **Category 3**: Changes in the diabetic patient's nutrition, sub-category 3.1 Culture: positive reinforcement from childhood.

Culturally there are habits fostered in childhood, all of them related to special gratifying moments that give advantage from food consumption; talking about changes in nutrition represents a "penalty" or loss to the individual and it is not willingly assumed with pleasure and consistency [20]. Nutrition style, central axis for diabetes control, is not easy since food has an intrinsic value culturally determined. Diabetics are used to special food because they are used at home and surroundings, food has a unique significance since it is associated with delightful or unpleasant experiences.

[] *This was awful to me, I do not really follow the diabetic specific diet, because my dad used to say "if I am going to die of diabetes, then do it so and if I have it does not matter". But a fight starts here since you realize that your body*

is damaged; metformin was prescribed to me and when I used it glycemia dropped, however its current use dropped sugar mildly, and any stress causes hyperglycemia. E4.

Sub-category 3.2 Constant mourn

Diabetes control has been unbearable in our culture since, in general, every social activity is associated with food consumption, and a diabetic must face this reality: how to be social? Because to cope with friends and others, an essential condition is to eat the food offered by them. As shown in the following speech:

[] *My food list changed a lot, and I get tired very easy since I am not as normal as the others, you get sick from any illness, you must be aware with what you eat: things that were normal in your daily life and now they changed, every day I get a shot of insulin.* E2.

We learn to nourish by our relationships with other people. From birth, eating is a social act, and this eating-related sociability is kept along our lifetime, up to the point that for the majority of people eating alone is unpleasant, overlaid with a sadness sensation due to social deprivation; food and the act of eating are associated with experiences distinct from just nutrition, as observed:

Sub-category 3.3 Pleasure by forbidden foods

[] *It is easy to say that you will modify your habits and that you will eat healthy food. I try to eat fruits, vegetables and eat well, a lot, but always you get the need to taste something sweet, and when you realize it already you are with a candy in your mouth and several in your bag, and with a sweetened soda because it makes you feel good, and then at night you get up to drink it because you are thirsty... even though you know, that is not ok.* E3.

To be out of family habits about diet lead individuals to sense they are really outside, not belonging and excluded, which is hit their mood and lead them to stop their decision to change nutrition, increasing their mourning, anger and defiance. During relapse or crises phases it is common to observe symptoms of depression, anxiety, and anguish generated by hospitalization, perception of health decay, the onset of new symptoms related to the disease, or the re-appearance of some others that were kept under control [21]. Then uncertainty in the patient occurs as the disease evolution is unpredictable, the continuous menace to life and the loss of hope to be cured.

When family members incorporate convinced to changes, anger and the refusal to change diminishes, converting the shared eating in a family act that integrates all members in the dynamics, favoring acceptance and belonging, removing the ill tag [15]; as shown in **Category 4: Benefits in the diabetic patient**, with the sub-categories 4.1 Need to be in a support net, and 4.2 Bonding ties and love by relatives

[] *You know, I am very tired of the disease, and sometimes I say... well if I have to mmm to die I will rest forever, but my wife is there, she is strong and always supported me, she is now working but comes and bath me, cares about me, I do not want to fail her, leaving her.* E2.

Bonding is an intimate and profound relationship that establishes among human beings; it is long-lasting, stable and conscious, and permanent in the life of a person. Bonding theory raises the innate human need to generate close affective ties, it manifests in stressful moments triggered by an external or internal threat; no matter what bonding type a sick person needs a close partner to motivate the self-care, encourage and fight together. Bonding is developed from childhood and significantly influences in processes such as mate choice, as well as the quality of affective relationships to be established in adulthood [15] [22] [23].

5. Conclusion

Relational, intrapersonal, material, and progressive losses that add to the Diabetes Mellitus chronicity between the couple: patient and family caregiver are a lot and accompanied by negative emotions during long periods of time; facing the role change, independence loss, changes in nutrition, among others, to reach care goals and limit patient damage feed the couple with positive emotions. The starting point is the perception of the news of the diagnosis; if this reality is accompanied by thanatology support to diminish the denial and anger step when realizing the change in health, then the perception of this first mourn and those to come along the disease course will be positively modified. Thanatology or health counseling support to the couple will favor that the patient keeps the disease under control and accept such modifications in its daily life, both consciously or unconsciously, as part of its values and attitudes without anger and denial along the disease chronicity, to have a better quality of life, and in the caregiver the importance and comprehension of attention and care it gives. The caregiver must not assume patient responsibility; its role is to accompany and, with the health team, along the course of the disease. The importance of health counseling by nurse professionals is based on effective communication that recognizes the user as the main actor in adopting healthy behaviors and self-care, being nursing a facilitator in the process of taking consciousness, decisions and activities of the person.

Authors Contributions

All authors collaborated in the research. DCTP, LVH designed the protocol and wrote the manuscript. DCTP and RVM revised and edited the manuscript for publication. LVH, DCTP collected and analyzed data. All authors read and approved the final manuscript.

Conflicts of Interest

Authors declare no conflict of interest.

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