The person with diabetes: from a therapeutic to an existential focus*

A PESSOA COM DIABETE: DO ENFOQUE TERAPÊUTICO AO EXISTENCIAL

LA PERSONA CON DIABETES: DEL ENFOQUE TERAPÉUTICO AL EXISTENCIAL

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ABSTRACT
This study was motivated by the aspects lived by people with diabetes and the implications the disease have on their lives. In essence, this study was performed with the purpose of changing the disease from its position of a fact to the position of a phenomenon that needs further clarification. Phenomenology was the framework used in this investigation, with a view to undertaking the meaning of living with diabetes. The study location was a health institution in the city of San Luis Potosí, Mexico, where people with diabetes were interviewed and provided statements about their experience. Data analysis permitted the construction of thematic categories, which revealed important facets regarding these people’s existence. The study provided new perspectives for looking beyond the disease, and seeing the person with diabetes within their situational context, thus, showing some paths for health care policies.

KEY WORDS
Diabetes mellitus.
Chronic disease.
Qualitative research.

RESUMO
Realizou-se este estudo diante da inquietação com a pessoa com Diabetes, as implicações da doença em sua vida; fundamentalmente, buscando um deslocamento da doença sob a ótica de um fato para a de um fenômeno, que requer desvolvermastos. Conduzido sob o referencial da investigação fenomenológica, com vistas à apreensão da essência do significado de conviver com a doença. O estudo foi realizado obtendo depoimentos de pessoas que experienciam a doença. O contexto da investigação foi uma Instituição de Saúde, localizada na cidade de San Luis Potosí, no México. A análise dos dados possibilitou a construção de categorias temáticas, que revelam facetas importantes do existir dessas pessoas. Abriu perspectivas para um olhar para além da doença, contemplando a pessoa diabética em sua situacionalidade. E assim norteando alguns caminhos para políticas de assistência.

DESCRIPTORES
Diabetes mellitus.
Doença crônica.
Pesquisa qualitativa.

RESUMEN
Delante de la inquietud con la persona con Diabetes, de las implicaciones de la enfermedad en su vida y, fundamentalmente, buscando comprender la enfermedad como un fenómeno, ya que hasta ahora ha sido observada como un hecho, se realizó este estudio, tratando de obtener de revelaciones la información que ayuden a alcanzar el objetivo pretendido. Conducido bajo el marco de la investigación fenomenológica, con el objetivo de aprehender la esencia del significado de convivir con la enfermedad, el estudio fue realizado obteniendo declaraciones de personas que experimentan la enfermedad. El contexto de la investigación fue una Institución de Salud, localizada en la ciudad de San Luis Potosí, en México. El análisis de los datos posibilitó construir categorías temáticas que revelaron facetas importantes de la existencia de esas personas, abriendo perspectivas para observar más allá de la enfermedad, contemplando a la persona diabética en su situación integral, mostrando, así, algunos caminos para la creación de políticas de asistencia.

DESCRITORES
Diabetes mellitus.
Enfermedad crónica.
Investigación cualitativa.
INTRODUCTION

As a Nursing student, the experiences of caring for ill people became very relevant as I started realizing that biological, psychological and social spheres of this care process demanded perspectives other than those stemming from technical-scientific procedures only. In this sense, there are perspectives that consider disease to be constitutive of the human being structure, an experience that should be dealt with within the healthcare context, describing ways of coping with its occurrence and offering opportunities that could produce a positive conception of diseases from a broad point of view\(^{[1-2]}\).

Some questions started upsetting me and, as a result, my look started being directed to the disease from another perspective: How does an ill person feel being bound to a bed in a hospital, totally depending upon the care of a nursing team? What meanings does he/she assign to his/her hospitalization?

Throughout the graduation course I learned that the care giving for a sick person can be provided within several contexts, such as, for example, their own homes. In most of the times, this practice occurred with patients who presented chronic degenerative diseases.

The anxiety generated within the hospital context was reaffirmed, even though under other configurations, thus opening way to new arguments. The idea of caring for the ill person instead of caring for the illness had already become a relevant issue, demanding the establishment of an empathic relationship and causing the healthcare professional to be on the other’s shoe in order to better shelter and understand the patient’s disease process.

Further, as a professor in the city of San Luiz Potosí, Mexico, I started looking more carefully at people with Diabetes Mellitus as I was given the opportunity of relating to them in their homes by means of the community nursing practice. This practice complemented and broadened my experience with people with chronic diseases who need healthcare assistance in their own homes.

The context of the disease and its dimensions

Diabetes Mellitus, recognized by humanity as a medical problem for ages now, is considered as one of the major causes of deaths in the world. It is a chronic-degenerative syndrome that encompasses a wide array of clinical causes and manifestations, having as a common ground the increase of blood glucose resulting from the reduced production of insulin by the pancreas or from the inadequate action of this hormone, causing the metabolism of the glucose, proteins, fats, and mineral salts to be affected\(^{[3-4]}\). There are two types of primary Diabetes that are especially distinct by the way insulin acts in the glucose metabolism. In type I, called insulin-dependent Diabetes Mellitus (IDDM), beta pancreatic cells located in the islands of Langerhans are damaged and the production of insulin is minimized or totally eliminated due to a mechanism that has not yet been fully described.

Given its epidemiologic nature, the Diabetes Mellitus represents a serious Public Health problem in the world. In 1985, the World Health Organization estimated that it affected 194 million people in the world. This international entity forecast that the disease will have reached 333 million people by 2025. The vast majority of cases take place in developing countries.

Mexico takes the ninth place in the world rank of Diabete-s. The predictions for 2005 indicated an incidence of 400 thousand cases, that is, 400 thousand new cases a year. The disease floats between six million, five hundred thousand and ten million (national prevalence of 10.7% in people between 20 and 69 years of age). From this amount, two million people have not yet been diagnosed with the disease\(^{[5]}\).

The Mexican Federation of Diabetes alerts that mortality rates have been increasing in the last decades; since 1997 Diabetes is ranked as the third cause of deaths in the country, currently recording 49,855 annual deaths\(^{[6]}\). This means that five people die every 60 minutes as a consequence of this metabolic alteration in the organism.

There have been hundreds of investigations carried out on chronic patients, especially those with Diabetes. The majority of them stir investigators to understand the responses of patients towards coping with their disease. The development of studies of such nature in patients with chronic diseases acquires relevance and contributes to the improvement of a high percentage of population. There is a high medical attention demand in this field throughout long periods of people’s lives\(^{[6]}\).

The vast investigative production concerning patients with Diabetes has been allowing for the sequence of care giving programs. However, results have not been favorable due to the secondary conditions that arise along the way. Therefore, it is quite relevant to keep studies up in such a way that better life conditions are reached to these ill people, taking into account that this disease is related to negative feelings, such as shock, revolt and sadness.

It is quite relevant to keep studies up in such a way that better life conditions are reached to these ill people, taking into account that this disease is related to negative feelings, such as shock, revolt and sadness. Whenever we look at Diabetes Mellitus from a factual standpoint we will be only concerned at conceptual explanations, descriptions of the disease’s symptomatology, multidisciplinary assistance protocols focusing the explanatory perspective of a certain conception of science that is far from the knowledge of a human being being inserted into the world, experiencing an illness condition.

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In this sense, the development of a qualitative-based study can reach beyond the quantitative context, once it allows for the investigation of the free expression of those who experience the process of being sick, a process that transcends the context of the disease and its determining agents.

As such, my purpose is to fill a gap in the production of knowledge on the Diabetes Mellitus, directing my look at the ill person not from the factual standpoint, but seeing the disease as a phenomenological experience in itself, aiming to unfold new horizons of comprehension of the patient’s reality before the disease.

**OBJECTIVE**

The purpose of this present investigation was to understand or capture the meaning assigned by patients to their daily experiences with Diabetes Mellitus in their world contexts.

**METHOD**

The theoretical-methodological reference of the study was grounded on the concepts of the phenomenology. My proposal was to apprehend the essence of a person’s existence with Diabetes Mellitus and, in this sense, I consider the phenomenon of experiencing this situation from the perspective of those who undergo the disease. The phenomenology is not concerned at generalizations, principles and laws. It focuses on describing phenomena, not on explaining them, and it does not intend to search for causal relations. The objective of the phenomenology is centered on the sense of unveiling, not demonstrating. Thus, phenomenology started being defined by Husserl as a descriptive science of the essence, the consciousness and its acts.

The phenomenological research, therefore, searches for the meanings subjects assign to their experiences, and these meanings are revealed from the description of those subjects.

Such meanings can be apprehended through the descriptions people make of how they experience a certain situation. Empathy is the access key researchers have to use to unlock the person’s investigated world.

The phenomenological investigation is built on what makes sense to the investigated subjects, placing the phenomenon in suspension and depicting it exactly the way it is perceived and manifested by language. It is necessary to move towards the perceiving subject and search for the senses he assigns to his experiences, having the comprehension of what is being investigated as a major goal.

Thus, the methodological design of this study was based upon some of Husserl’s ideas. Nonetheless, as indicated by the title, I searched for a displacement movement from the therapeutic standpoint of Diabetes to the application of an existential approach. In some of the analysis, this move demanded an appropriation of some of Martin Heidegger’s ideas. Walking on Husserl’s paths, this philosopher brings new ideas to the phenomenology. These ideas allowed me to scientifically ground the comprehension of the discourses concerning the existential sphere.

**Data Collection**

Data were collected by means of interviews with people with Diabetes who were cared for at a Social Security Institution called Francisco Padrón Poyuo, located in the city of San Luiz Potosí, Mexico. These people were part of the group of patients with Diabetes assisted in the preventive medicine ward. I also looked for sick people enrolled in the same Institution who are assisted at home by means of a specific program fit to chronic patients.

Before the data collection process, I decided to access the Service in order to get acquainted with this world populated by ill people and healthcare professionals. As such, I started spending much of my time with people who worked and lived in that place, sharing their activities, apprehending the group dynamic. After this initial period, I invited people with Diabetes to participate in the study. I invited those people who were living with the disease for at least one year, in such a way that they were able to talk about a certain amount of time experiencing the illness.

I met the investigated people in the context of their own homes. My purpose was to apprehend them within their worlds of experiences and body perceptions of life, based on their statements about the following question: What does it mean for you to live with this disease? Give me a description of what it is to be a person with Diabetes. Ten people were interviewed, before the data collection process was saturated. This is the criteria the phenomenology applies to discontinue any data collection process. The saturation expresses that the phenomenon is already able to show itself, in its very essence.

The intention was to capture their remarks on the time of experiencing the disease and their interpretation of their human relationships with others and with themselves.

The employed methodological resources were the interviews and the field diary, in which I recorded some perceptions beyond the verbal discourses, that is, every single possible sphere of the manifestation of the Being by the non verbal language: gestures, facial expressions, reluctant silence, quietness, affectivity, emotions, contentions of emotions; in a nutshell, what is said and what is not said.

By observing and analyzing the discourses I searched for the unfolding of the way those people live in the world, in their condition of being with the Diabetes.

The study complied with the dispositions of the Mexican General Healthcare Law’s Regulatory document concerning healthcare-oriented investigations (Health Secretariat 1987). The observations proposed by the Committee of Ethics of the Celaya Nursing School, Guanajuato, were incorporated into the study.
Right after accepting the invitation to participate in the study, the person received clear and concise information on the justification and objectives of the investigation, acknowledging specific details on how the interview would be carried out. Participants were also communicated on the possibility of giving up at any time, without any loss to either their treatment or relationship with the Healthcare Institution in which they were inserted into. It was also explained that all data that allowed for their identification would be kept under secrecy, thus respecting their privacy. The Term of Free Consent was signed up. Interviews were recorded under the agreement of each participant.

CONSTRUCTION AND ANALYSIS OF RESULTS

Based on some core ideas of the Phenomenology, the present study was aimed to search for the essential structure of the investigated phenomenon. The statements of the interviewed people signaled to the spheres of their existence that had been affected by the disease. These existential facets found relevant analytical subsidies in the heideggerian thought [11].

The analysis made possible the construction of four thematic categories that expressed the essence of what being a person with Diabetes meant. The categories were built in accordance with the steps recommended and explained by some authors [12-14].

- The researcher reads through the description aiming to apprehend its whole sense. Then he familiarizes with the text that describes the lived experience. He attempts to put himself on the subject’s place so that he is not only a bystander, but someone who tries to grasp the meanings attributed by the subject exactly on the same way he sees it. This operation is a must in the phenomenological modality.

- The researcher reads the description once again, now in slow pace, pinpointing units of meanings. There are no specific guidelines to this identification. At this point, the interaction between the researcher and the investigated subject emerges; it is necessary, then, to take into account that the process of categorizing the qualitative material will involve not only a logical, intellectual, objective knowledge, but also a personal, intuitive, subjective, experiential knowledge. When the researcher assimilates units of meaning he is acting according to his own perspective, focusing the phenomenon that is under investigation.

- After achieving units of meaning, the researcher goes through them and expresses the meanings therein. This is particularly true to the more revealing units in the considered phenomenon. It is implicit that one of the criteria is the frequency that phenomenon occurs; however, it is not the only one. Data may contain aspects, observations, comments, unique characteristics that can end up becoming extremely important to a wider apprehension of the studied phenomenon. There will also be non intentional, implicit and contradictory messages that, in spite of being unique, will reveal significant dimensions of the situation.

- Finally, the researcher synthesizes the units of meanings in order to reach the structure of the phenomenon and its essence. In this synthesis the researcher integrates the insights contained in the units of meanings that were transformed into a consistent description of the structure of the phenomenon.

Religion permeates the daily experience of the disease

The discourses reveal that after the onset of Diabetes, people need support and eventually find it referring to the disease as a divine test. Mention is made to a punishment from God:

Pues para mí todas las enfermedades son… mandadas por Dios, pero no nos da más, más de lo que se pueda soportar, él siempre nos manda los medios para… pues para ya sea para este, sobrellevarlas o convivir con ellas [15] (Statement 1).

...Ay Diosito porque me castiga, pero a pesar de que uno esta malo, diosito no lo castiga a uno así, si diosito es amor, y uno le tiene amor a Dios como lo va a castigar a uno así, y dice uno pues bueno te encomiendo esta enfermedad ahi te la entrega, pero yo digo, que diosito no me castiga así, soy mala si, soy mala porque digo, no creo que diosito diga que de castigo me manda esta enfermedad, no, no creo, Dios le tiene amor a uno (Statement 6).

Some understand that God may be sending an advice, using a disease to alert people on their need to begin a new life:

Dios me esta poniendo algo para vivir mejor los últimos días que él me quiera mandar, son pruebas que Dios nos pone para crecer mejor, para crecer mas, (repite) para crecer mas… (Statement 1).

There is also a mention that the disease may mean a punishment from God due to bad habits, especially food-related ones. Observe this statement:

...porque el estar cerca de Dios pues refortece, y hace uno consciente de que, pues si todo lo tengo lo tengo de él, pues por algo lo tengo, lo que me pasa en la vida es por mi desorden de vida ehh, yo me lo busque, por mi forma desordenada de comer y , pero, si he dejado algunas cosas pero a mí no me parece importantes (Statement 4).

However, the assignment of meaning to the disease as a punishment is somehow ambiguously verbalized, once as soon as they utter this belief, they discard it:

...ay Diosito porque me castiga, pero a pesar de que uno esta malo, diosito no lo castiga a uno así, si diosito es amor, y uno le tiene amor a Dios como lo va a castigar a uno así, y dice uno pues bueno te encomiendo esta enfermedad ahi te la entrega, pero yo digo, que diosito no me castiga así, soy mala si, soy mala porque digo, no creo...
Coping with the disease is part of the existence of the person with Diabetes

Discourses express that the disease requires a fighting back posture by those that experience it. Such behavior affects the people’s whole existence and is shaped under various designs: accepting the disease, understanding the limits the disease imposes in several spheres, such as times and types of food, using hypoglycemic agents, and many times treating related diseases, such as hypertension. Living with those people and referring to the observations noted down on the field diary, as well as in the way each of them appeared to take a posture of confronting the disease, regardless the configuration it takes on, will lead to a way of experiencing the illness. Observe their statements:

...yo soy diabética y... así tenemos que ser, si no hay esta enfermedad, a lo mejor después yo valoraba y decía, ¡Gracias Dios mío por que soy diabética y no tengo cáncer! ... (Statement 2).

In this sense, the person’s understanding of his religious belief can open paths to the dialogue and to ways of accessing the person’s existence, motivation, singularity[15].

It is worth mentioning that the religious dimension is integrated here, even though in an embryonic way, to the healthcare assistance, featuring new caring modes, including the subjectivity, the respect for the person’s religiosity and mainly the fact of considering religious beliefs as essential elements in caring for the ill person[15].

Expriencing Diabetes

In the beginning, statements referred to the moment of the diagnosis as a hard time, often generating sadness and sometimes, depression. Dealing with those feelings has...
The person with Diabetes and his temporality

The issue of the temporality emerged in several excerpts of people’s statements. Some clearly indicated that there is a necessary knowledge required to control the disease. However, certain control measures, especially regarding foods, were not incorporated. The restriction seems to instill even deeper sufferings compared with the evolution of the disease itself.

Another observation was the certain degree of doubt concerning what will happen to them, in spite of following the healthcare team recommendation:

...ahora lo que me queda es de cuidarme y de que estar con la medicina y ya porque no creo que se me vaya a quitar, porque dijera que, ¿no puede ser que ya me componga por decir con la dieta? y que, ¿ya no use medicina?, eso, eso no puede ser ¿verdad?, y así estar yendo cada mes al seguro, cada mes voy (Statement 3).

It is interesting to observe that this declaration contains an interrogative tone. It is possible to verify the same tone in other statements, expressing insecurity towards the sequence of the treatment.

We should, then, question: What would the genesis of this insecurity be? Are the healthcare professionals succeeding in finding a path towards the subjective dimension of the person?

Heidegger reminds us that man is, above all, a being of projects. Whenever his projects are too restricted, his existence can become a void. Naturally, as years go by and these people live with the chronic disease, existential projects need to be re-dimensioned. However, the statements do not allow us to observe strong commitments concerning this re-dimensioning process. People seem to fatally, rather than factually, face the disease.

Thus, a number of them verbalize their deep concern at the complications of the disease. They know of the existence of risk factors concerning amputations. In other moments, the statements follow another trail, and they verbalize that their lifestyle somehow changed, preparing them to live with the disease and catch a glimpse of a future project:

se que el final es… (Hace un silencio) lo máximo si lo sé, tomo mis medicinas en orden, bueno, mas o menos, a veces se me olvida a medio día y pues así ay la llevo, voy a estar bien, de aquí en adelante, voy a intentar tomar mis medicamentos y controlar mi alimentación, para que en un futuro me encuentre mas aliviada, intentaré seguir en el grupo, y restringirme los chocolates, y hacer un poco de ejercicio, como salir a caminar (Statement 10).

Man is a fundamentally temporal being; thus, he has a history and has an ontological limit, which is death. Each moment of time—past, present and future—is not restricted to itself. Future is yet to come and should not be understood as the now that has not chronologically come yet,
but rather in the sense that I am my future as soon as I come out of myself, as I open myself to the possibilities, as I take care of my own being\textsuperscript{[21]}.

The past is the factibility and should not be understood as something that is way behind us, but as something that now affects my existence, once the past is always present, shaping our lives. The present is the condition of the possibility of being in the world.

Some people’s statements clearly express such a reference. They perceive the disease is now part of their world and, in this sense, verbalize the acknowledgement of the necessary controls in order to maintain a good quality of life. At the same time, some of them resist abandoning habits they acquired in a diseaseless past, even though they know that they will affect their future, or their yet-to-come existence with the disease. This phenomenological framework forwards us to the authenticity/inauthenticity concept, an issue Heidegger developed with precision. Every man experiences moments of authenticity and inauthenticity towards himself and everything surrounding him. Thus, the attitudes of people at what happens to them, at the restrictions imposed by a given disease, will dynamically express such a duality. They know that this yet-to-come existence can bring several complications and, therefore, some people clearly utter their fear towards amputation, blindness, the possibility of losing their mobility capacity, in a whole, the capacity of taking care of themselves.

Hence, the experience of being affected by the disease is bound to their being sick, and their yet-to-come existence is aligned to narrower horizons. Their ontological condition of being-for-death is more visible before the way they experience the disease. Some statements bring the verbalization of death not only as a possibility inherent to the human condition, but as a situation that is potentialized by eventual complications of the Diabetes.

It is also possible to notice that their participation in support groups instill some degree of transformation in the way they experience the disease, and produce a higher level of comfort in this future perspective. Again, here is another urgent need healthcare professionals have of capturing the ill person in his being-sick status, in such a way that these professionals can find pathways to their being.

Regarding the nursing activity, nurses can focus their questions, senses, behaviors, theoretical and factual data on other perspectives. The disease, as it is experienced by people, has two aspects to be taken into account. First, there is a structural and formal nature that allows for the understanding of the disease in itself, anywhere in the world. The second will express the concrete existential condition of the sick person, connected to each one’s own history.

As this study pointed out, the patients’ temporalities were present in their statements, unfolding some of the spheres of time. This information can highlight tracks healthcare professionals can follow towards care giving processes. Thus, once again, healthcare professionals have a critical need of assimilating the ill person’s being-sick status, so that they can run across access ways towards these patients’ being.

FINAL CONSIDERATIONS

Reflections on the unfolding

My experience with people with Diabetes was driven towards another direction. Diabetes, previously understood as a metabolic alteration of the organism and seen only as a fact, started gradually requiring a more comprehensive attention to the person in his being-sick status. This study made possible the unfolding of facets that signal the essence of this experience.

Man’s attempt to domain everything reveals his endeavors to build a safe, predictable, controllable, constantly comfortable world to himself. However, the existence does not uphold such a sense of safety. The existential adventure steadily forwards us to the presence of the unsafe, the unpredictable and the uncontrollable, showing us the cruel dimension of the world.

That’s why people who talked about their experiences of living with the disease showed us their changes of habits to prevent complications, including death, questioning what could happen to them. In their existential history they confirmed their knowledge of the necessity of re-dimensioning their lifestyles, in order to improve their quality of life.

I believe that this reflection is highly necessary to healthcare professionals. We can not presume that all information has been given, that all orientation was provided. Humans have a dialectic nature, permeated by moments of acceptance, denial, approach, withdrawal, authenticity and inauthenticity. These are all ways of being in the world. The vision of an existential movement may be all that healthcare professionals need to reverse unsuccessful treatments.

A multidisciplinary and interprofessional work must be effectively done, focusing the sick person as the subject of our attention. We should not take on the connotation of a group of people that only works together.

In our everyday work as nurses we often see ill people undergo hard moments of decision. We can help them by understanding them in these moments. Decision-making processes are not linear actions. It takes place in circles. These moments, therefore, are conflictive, ambiguous and contradictory, as they are human productions.

When nursing professionals get rid of the old-fashioned and inconsistent concept that they should not get emotionally involved with the patients, they will be able to employ their subjectivities to capture the subjectivity of the sick person, establishing inter-subjectivities that will make the nursing care an easier practice. All in all, the nursing practice will be highly benefited, once it has access to
The ill person in the care practice by means of professional techniques, and this connection is mediated by this access to his body.

The commitment to create human connections is still a big challenge, once it demands the professional to also approach his own incomplete, fragile existence. This commitment leads healthcare practitioners to rethink the formation and organization of services, the inclusion of the caregiver in the assistance process, the interconnection between the Philosophy and the deconstruction of old healthcare policies aiming to a reconstruction grounded on principles that envisage, above all, the essence of the person to be cared for (17-18).

The healthcare and the educational fields are closely connected to the care human beings need; the perspective by which we conceive man imprints a sense, a direction to the way we think and do things. These actions are expressed in formulated policies, labor organization, and built social and interpersonal relationships. For this reason, healthcare institutions and professionals have attempted to establish and activate educational programs that are able to help in the way the person sees the disease, the meanings of changes and the re-dimension of his existence.

The person with Diabetes expects care giving professionals to provide him with human engagement, the establishment of bonds, and a personal availability to be with him. In this sense, the professional’s self is a valuable instrument in the relationship with the sick person, and he should set a body of strategies that is able to humanize assistance practices.

The nursing care must be based upon the following question: what type of man does this care envision: the subject in which science is manifested, or that being-in-the-world subject who is always a yet-to-come being, that is, an unfinished project?

The answer must be built by healthcare professionals in their care giving practice. In this sense, a significant portion of this construction is directly related to nursing professionals.

REFERENCES


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