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Psychosocial factors that influence the doctor-patient relationship in the clinical genetics consultation.

Factores psicosociales que influyen en la relación médico paciente en la consulta de genética clínica.

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Summary.
Introduction: clinical genetics has been recognized as a practice dedicated to the diagnosis and management of genetic disorders by the medical geneticist. However, data on how the clinical genetics consultation works in Colombia are non-existent and without information about the challenges in caring for the population with genetic disease. The objective of this study was the psychosocial characterization of the clinical genetics consultation in a private, highly complex hospital in the city of Cali, Colombia. Methods: this study was carried out by combining observation and a semi-structured interview with two medical geneticists from a private health institution in Cali, with fourteen observations and two interviews. Results: factors, internal and external to the consultation, that influenced its dynamics were identified: the barriers in the health system, the type of consultation and the personal factors of the geneticist doctor. Conclusion: the comprehensive care of people with genetic conditions must transcend the biological approach, in deficiency, to an approach that also considers psychological and social aspects.

Keywords : Genetics; genetic counselling; clinical competence; Physician-Patient Relations.

Resumen.

Introducción: la genética clínica ha sido reconocida como una práctica dedicada al diagnóstico y al manejo de los trastornos genéticos por parte del médico genetista. Sin embargo, los datos sobre la forma como funciona la consulta de genética clínica en Colombia, son inexistentes y, sin información acerca de los retos en la atención a la población con enfermedad genética. El objetivo de este estudio fue la caracterización psicosocial de la consulta de genética clínica en un hospital, privado, de alta complejidad, de la ciudad de Cali, Colombia. Métodos: este estudio se llevó a cabo combinando la observación y la entrevista semi-estructurada a dos médicos genetistas de una institución de salud, privada, en Cali, con catorce observaciones y dos entrevistas. Resultados: se identificaron factores, internos y externos a la consulta, que influyeron en su dinámica: las barreras en el sistema de salud, la tipología de la consulta y los factores personales del médico genetista. Conclusión: la atención integral de las personas con condiciones genéticas debe trascender el abordaje biológico, en la deficiencia, a un abordaje que también considere aspectos psicológicos y sociales.

Palabras clave: Genética; asesoramiento genético; competencia clínica; Relaciones Médico-Paciente.

1. Introduction

Clinical genetics is a specialty of medicine dedicated to the diagnosis, prevention, prognosis, and management of genetic disorders associated with disease (1). This specialty constitutes the healthcare/clinical component of genetics and represents the broad field of scientific knowledge dedicated to genetic variation, biological inheritance and their respective implications and applications in the field of health. In this sense, the clinical practice of the geneticist encompasses, by definition, the diagnosis, care and follow-up of patients with specific genetic diseases, as well as genetic counselling. For Batlló and Batlló (2), medical diagnosis is the process through which the professional names the patient's suffering. To obtain it, it makes use of tools such as anamnesis, clinical history, physical examination, and laboratory/complementary tests, with the aim of identifying symptoms and signs that allow it to associate or rule out what it is observing with a specific disease or pathology. Achieving expertise in the medical diagnosis process depends on practical experience (3). In this sense, much of the training in medicine is based on the possibility of interacting with subjects who live with some health condition. Since the time of Hippocrates, the diagnosis of the disease and its natural consequence, the prognosis on its evolution, has been considered the central nucleus of medical knowledge, which accounts for a profession that is based on knowledge justified by experience and not on simple intuition or discursive resources, reasonable but unfounded (4, p.150).

On the other hand, genetic counseling is a process through which patients and relatives are oriented about the risk of having a hereditary disease, its causes, its consequences, its management; and, sometimes, attention to the psychosocial needs of this binomial (5), since the genetic disease "not only affects the physical condition, but also the mental and social health of the patient and his family", which assigns to genetics clinical responsibility to support them in all aspects through the clinical encounter (6, p.39). In Europe, clinical genetics services are in charge of doctors trained in the area, and the function of genetic counseling is carried out by professionals trained specifically for this task, not necessarily doctors (5). However, Spain is the only European country where the specialty is not recognized; situation that has become one of the causes of activism on the part of the Spanish Association of Human Genetics (AEGH) and the Spanish Federation of Rare Diseases (FEDER). Meanwhile, in Colombia, as in most Latin American countries, the geneticist doctor is in charge of carrying out all the aforementioned functions, including genetic counselling. However, there is no information that allows us to know how this medical practice is carried out in our country and, consequently, there is no information that allows us to account for the challenges that arise in the care of the population with diseases of genetic origin and their families, in particular spaces such as the clinical genetics consultation.

Orphan diseases of genetic origin, also called rare or minority diseases, are characterized by a low population prevalence. In Colombia, Law 1392 of 2010, recognizes them as diseases of special interest in health, chronically debilitating and with an occurrence of less than 1 case per 2,000 people. The low frequency of these conditions limits the achievement of expertise in the diagnosis and genetic counseling process, which is why human talent with this specialized knowledge is scarce in number and is usually concentrated in reference institutions. This situation translates into limitations in access and use of health services, especially for those people who live withdrawn from these reference care centers. Obtaining the diagnosis of a genetic disease, on the one hand, puts an end to a long period of uncertainty, however, it confronts the patient and the family with a situation of frustration and insecurity, since the communication of the diagnosis is often considered confusing (6). Once advances in diagnostic understanding are achieved

as a result of the translation of highly specialized scientific terminology, challenges common to all orphan diseases must be faced: lack of curative treatment, barriers to complementary treatments, and uncertainty of prognosis. In this sense, it is possible to imagine the significant overload that this situation generates, both for the patient and his family (5) but also for the treating physician in the process of dealing with it.

In this sense, the doctor-patient relationship takes on great relevance. In recent decades, the doctor-patient relationship has become the subject of numerous investigations aimed at understanding and improving the way professional doctors relate to and communicate with their patients. Emanuel & Emanuel (7) propose four relationship models whose structuring can occur in the field of medical consultation: 1) the paternal model, in which the doctor becomes the owner of knowledge with the aim of ensuring the health of the patient, considering their interventions as the "best" and "unique" since they are based on an objective knowledge of the topic; 2) the informative or consumer model, in which the doctor's objective is to provide sufficient information to the patient so that he can make decisions regarding his health; 3) the interpretative model in which the doctor listens and tries to determine what the patient wants at the precise moment of the consultation and even helps the patient to rediscover his values/desires to assume a joint search for health; 4) the deliberative model in which the doctor discriminates between values that can help the patient to recover optimal health and those that do not, his role being that of a counselor. Makoul (8), then Street Jr. & Epstein (9), contemporary referents in the study of the doctor-patient relationship, focus on the communicative aspect of the relationship, proposing communicative functions that should, initially, mediate the way how the doctor and his patient communicate within the consultation space. These functions are respectively: 1) function of promotion and care of the healing relationship, 2) function of exchange of information, 3) function of validation of emotions, 4) function of handling uncertainty, 5) function of support in taking decision-making, and 6) function of promoting autonomy. Likewise, Street Jr. & Epstein (9) highlight the existence of factors, internal and external, that influence the way in which the patient and the doctor communicate in the consultation space, such as age, ethnicity, personality, representations social, family context, educational context, among others. Internal moderating factors describe those personal aspects, such as age or stratum, which may affect the doctor-patient relationship in one way or another. Likewise, some of the internal aspects of the patient are referenced on which the doctor can exert influence to avoid tensions in communication; These are: educational distance, social distance, doctor's attitude towards the patient, patient preferences. The external moderating factors are referred to as important insofar as they are also prone to condition the way in which the doctor and the patient relate and communicate (eg family environment, media and health system). However, since they are not within the reach of the doctor, they are not the subject of further investigation.

Given the clinical complexity of orphan diseases and the challenges that this entails in establishing the doctor-patient relationship, the need to carry out an investigation was raised whose objective was focused on the psychosocial characterization of the clinical genetics consultation in a private hospital. of high complexity in the city of Cali, Colombia. The descriptive aspect of the characterization is given by the understanding of the interactions that arise or may arise in the doctor-patient and accompanying triad. While, the psychosocial aspect is found in the emphasis placed on events (external or internal) that could influence such interaction.

2. Methods

Subjects

The city of Cali concentrates the two highly complex health institutions that serve all the patients in the south west of the country. The selected institution has three geneticists, two focused on the pediatric population and one on adults. The two medical geneticists who care for minors voluntarily participated in this research. The procedures described in this study were developed according to the regulations on research ethics, in force in the country and defined by both the clinic and the Icesi University.

Process

An exploratory-descriptive qualitative study was carried out where various methodological tools were used. At first, participant observations were made to the psychosocial factors that influence the process of the scheduled clinical genetics consultation, in a period of time between August 3 and October 13, 2017, under verbal informed consent. of the patient and/or family member/companion. A total of 14 consultations were observed, 7 by each geneticist. In all cases, informed consent was obtained in accordance with the IRBB-EC 130 protocol, approved by the ethics committee of the Icesi University, corresponding to the professional practice project of the psychology program.

Instruments

In a second moment, a semi-structured interview guide was prepared that allowed the collection of information from the perspective of the doctors. Subsequently, the interviews were transcribed and the information was triangulated in order to establish the categories of analysis; For this step, the qualitative data analysis software Atlas.ti was used. In the participant observations, a logbook was used to record information related to the description of the consultation environment, the activities carried out, the participants, the interaction of the doctor-patient-accompanying triad, where it was considered: the verbal interaction and non-verbal, as well as the spatiotemporal aspects of the clinical genetics consultation, the different moments associated with the diagnostic process. In the semi-structured interviews, an interview guide was used that allowed collecting information from the following sections: general data of the interviewed doctor, professional vocation, aspects related to the clinical genetics consultation, aspects related to the clinical genetics patient, aspects related to the diagnosis and management of an orphan disease, considerations on the institutional framework and the development of professional work.

3. Results

Of the 14 consultations observed, 11 were from pediatric patients and 3 from patients of legal age who attended for genetic counseling. Consequently, most of the consultations observed had the presence of a responsible adult companion, who was generally represented by the patient's mother. Due to the nature of the university hospital, the presence of other actors during medical practice was identified: a doctor in compulsory social service, a research assistant doctor, a Pediatrics resident and a last-year Psychology student who carried out participant observation. Regarding the characteristics of the patients that allowed observation of the consultations, 8 were women and 6 men. One patient presented severe motor disability, with total dependence. Eight patients presented cognitive impairments. The doctors who attended the observed clinical genetics consultation have undergraduate training in medicine and a PhD in Health and Biomedical Sciences, both with an emphasis on genetics. The doctors of the observed

consultations have an experience of more than five years in the health institution. The results have been grouped into three categories of analysis that influenced the geneticist's relationship with the patient and his companion. Two of them related to factors external to the consultation: the barriers in the health system, which describe the area in which the relationship develops; and the typology of the clinical genetics consultation, dedicated to the description of the moments that characterize the clinical genetics consultation process. The third category is related to the internal factors in which are the personal factors of the geneticist doctor that influence the doctor-patient relationship. The results are presented below, ordered according to these categories. The voice of the doctors interviewed is integrated into the story.

Barriers in the health system.

Regarding the health institution where this work was carried out, it is found that it is a private institution, characterized by being a university hospital, a reference in the provision of highly complex services, which serves the entire population of the south west Colombian. As a result, many of the people who come to the clinic must travel from different municipalities to the city of Cali, in order to be seen by a clinical geneticist. The health institution to which the medical geneticists are linked is located in the city of Cali and has three of the nine specialists in clinical genetics in the city. "In Colombia, we have insufficient human talent in health to care for the population with orphan diseases, because until now, there is only one specialty in medical genetics that trains specialist doctors, which results in a reduced availability of doctors in this area" (personal communication, August 3, 2017).

Of the three existing consultations in this institution, two are pediatric consultations, that is, they attend to newborn patients up to 18 years of age or to pregnant mothers. These consultations are carried out by male specialists. Additionally, the time defined by the institution to carry out care for the first time is 30 min; and 20 minutes for control consultations. However, the professionals in the observed consultations dedicated one hour and 30 minutes, respectively, to each process, with the aim of deepening their work even when this meant going against the demands of the institution's productivity, the extension of their agenda and longer waiting time for other consultants. On the other hand, it is identified that the recognition of clinical genetics, both for the general population and for other medical specialties, is limited. This “invisibility” of the area becomes a barrier to care for the population with a disease of genetic origin, as one of the doctors interviewed stated: “…they arrive alone. In other words, there are times when I have received patients who say "I want a geneticist to see me because I know I have something and no doctor has known that I have it." But it is not usual. The usual thing is that it has been referred by a doctor, but in general, the norm is that the genetic patient is a multi-doctor patient; Many doctors have not been able to tell you that you have a genetic condition and many times they come to genetic referrals, not so much because the doctor thinks you have something genetic, but because they don't know what else to ask for, they don't know what else to do, and they say “well We are going to send him for genetics to see if he does know what it is” (personal communication, September 22, 2017).

Likewise, people with orphan diseases face barriers related to the authorization of diagnostic tests given their high cost for the system, which, in turn, delays the control appointment, becoming a circular problem.

Typology of clinical genetics consultation

We identified four types of consultation: the first consultation, diagnostic exploration, follow-up, and genetic counselling. In the first consultation, information about the patient

and his family is collected and the patient and companion are presented with a path, a process, which could eventually lead to the achievement of a diagnosis. The pattern followed for this query is as follows:

1. Inquiry into the reason for the consultation - which may or may not be known by the patient and his companion - and the family history.
2. Physical examination of the patient (eg, height, weight, head circumference, vital signs);
3. Communication of diagnostic possibilities.
4. Request for diagnostic tests and consultations to confirm the diagnosis.

The first consultation is also presented as an opportunity to "relieve the stress" that patients and companions carry as a result of situations associated with the uncertainty of the diagnosis. One of these situations is related to the growth of information technologies and their introduction into medical practice, since they generate the possibility of obtaining incessant information that generates more anguish in patients and relatives. Another situation that the doctor must face is the exhaustion in the struggle that these actors assume against the barriers of the health system, in which "the need for a diagnosis sometimes takes a back seat" (personal communication, 23 September 2017).

The following consultations, referred to in this research as "diagnosis exploration consultations"; They focus on comparing the initial diagnostic possibilities with the opinions of other specialists and with the results of the tests requested in the first consultation. Frequently, the most likely genetic condition is established and additional tests with greater specificity are requested to confirm the diagnostic hypothesis.

The diagnosis in clinical genetics triggers a series of emotional, psychological and social processes, both in patients and in their families (10). The companion can react in different ways to the diagnosis, however, none of the interviewees referred to planning a way to "break the news."

There are positive reactions because other health conditions are ruled out, and treatments can be obtained, if available. There are also negative reactions, with feelings of rage, associated with the "mourning" for the loss of a healthy child; guilt, due to ideas about the genesis of the situation; or fear, because this news could indicate a state of genetic risk for the rest of the family, “people, when you make a diagnosis, feel grateful; when you don't diagnose her, she's still grateful; but when you tell them you don't have anything, they get angry” (personal communication, August 3, 2017).

“It is a hard responsibility, since one is the one who has to place the diagnosis [on the patient] and doing it, is sometimes also putting up a sign that there is no cure, that there is no treatment, ending the faith” (personal communication, August 3, 2017).

“[…] It is necessary to be alert to all situations that can also affect the patient in some way, since there are times when they have nothing to do with the diagnosis itself, but with their surroundings; I have had many hyperactive children that I know that the main problem is not the genetic problem, but the social problem; you have to capture it and see if it can be managed and if it cannot be managed, refer it to a psychologist or psychiatrist […]”. (personal communication, September 22, 2017).

One of the negative feelings after diagnosis is guilt: “people want to blame anything” (personal communication, September 23, 2017). For example, “when a child with Down syndrome is born, 70% of the parents blame the mother” (personal communication,

August 3, 2017). In these cases, doctors have mediated in a respectful and timely manner, regarding the cultural and ideological beliefs of their patients and relatives. The foregoing highlights the psychological complexity associated with the process of delivering a diagnosis of genetic disease.

At this point, with the establishment of a diagnosis, consultations dedicated to the "follow-up and monitoring of the specific genetic condition" appear. Doctor 1 highlights at this point that the work of the geneticist focuses on "leading the interdisciplinary work" associated with the processes of prognosis, follow-up, monitoring and even treatment of the disease, because only for some conditions "there are treatments and even cures, especially for few diseases in which gene therapy can be performed. Thus, the work of the geneticist doctor revolves around the "evaluation and anticipation of what patients may have later" as a result of the evidenced genetic condition.

Genetic counseling can occupy a part of the follow-up consultation or it can be carried out in a consultation exclusively dedicated to this purpose. In this consultation, the demand of relatives for information on the inheritance and transmission of the genetic condition is met, and the geneticists present the clinical management options for these particular consultation situations.

The personal factors of the geneticist doctor that influence the doctor-patient relationship.

Regarding the geneticist doctor, it was identified that medicine and its care component were not manifested as fundamental for his vocational choice. In both cases, the interviewees chose medicine, specifically training in genetics, as a vehicle to pursue other types of interests related to science and research. In a certain way, there was a professional orientation towards the scientific/technical component above the relational/care component, which managed to integrate into medical practice. However, the approaches with which these two doctors approach their patients present marked differences.

Particularly, in the first consultation it is evident that Physician 1 favors a scientific perspective, focused mainly on answering the question related to the diagnosis. In this way, his strong clinical reasoning allows him, based on observation and the interview, to build objective descriptions about the body and the manifestation of the disease with the aim of approaching diagnostic hypotheses (11): it is then a question of “assembling , inside the head, if you have heart disease; if you have heart disease plus cognitive deficit; if he has heart disease, more cognitive deficit and one extra finger”.

For his part, Doctor 2 favors a more human perspective, focused on the psychosocial needs of patients. He considers the first consultation as a privileged space to "reduce the level of stress that patients come with" through conscious listening to their needs over the diagnostic need. This is also evidenced in the representations that both doctors have about the patients who attend the genetics consultation. To illustrate, Doctor 1, with a look guided by the biomedical paradigm, refers that "in two days of consultation, 30 different pathologies can present" and, in this sense, the genetic consultation becomes a scientific research scenario , where patients become “research questions” or “challenges”.

Meanwhile, Physician 2 introduces a conception of the patient with a different genetics, stating that he himself is nothing more than a person with "a syndrome that has a condition in which there is a gene that produces certain clinical characteristics, which with certain management doctor can lead a practically normal life", at the same time, he makes a reflection in which he states that society has "the mistaken idea that everyone has to be

normal" and that, consequently, the word abnormality serves to describe those who do not present characteristics according to the average.

These differences in the approach can be explained from the vital history of each doctor and the subjective construction that he has made of his professional practice. In particular, Doctor 2 shares that having a child with a genetic condition has facilitated an empathetic approach with his patients, since he is positioned as a doctor, but also as a family member.

Regarding the clinical genetics patient and his companion, it should be noted that the analyzed genetics consultation attends to the underage population, therefore, a constant is the presence of at least one companion represented by a family member or who plays the role of main caregiver . The figure of the patient-companion pair is understood by the doctors interviewed as a unit that exhibits different needs "the genetic consultation is for the patient and his family" (personal communication, August 23, 2017). Observations reveal that when patients have cognitive disabilities, doctors establish communication with the companion and not with the patient, even when they are in advanced stages of the life cycle, such as late adolescence (personal communication, August 24, 2017). Physician 1 refers that the doctor-patient-accompanying relationship manifests itself in this way because "the patient does not understand and it is the accompanying person who understands the diagnosis." On the other hand, it is necessary to take into account that the clinical genetics patient and his companion, before arriving at the consultation, "have gone through various specialists who have not been able to find the diagnosis, so they are eventually referred to the genetic consultation hoping to clarify the patient's condition" (personal communication, August 23, 2017). In general, the clinical genetics service is at the end of a journey through multiple medical specialties through which patients and their companions have passed. This circumstance can be explained by the very difficulty of diagnosis, given the wide spectrum of presentation of some conditions, and by the scant knowledge that non-genetic doctors have about most genetic diseases.

This forced transition through the health system makes patients more recursive and assertive in their interaction with it, but due to the uncertainty of the diagnosis, when they arrive at the genetics consultation they assume a more demanding position in front of the doctor, which, although it could be used as an opportunity to build the doctor-patient-accompanying relationship, can also be seen as an obstacle in a paternalistic and vertical model.

4. Discussion

Carrying out a characterization of the clinical genetics consultation focused on psychosocial aspects, was of vital importance in the care of the population with orphan diseases. Understanding its complexity made it possible to identify the challenges faced by medical geneticists in their professional practice, related to the existence of a series of psychosocial factors, internal and external to the clinical genetics consultation, that influence the relationship between the doctor, the patient and their caregiver, who is usually a woman.

Evidence shows that one of the key factors to address these challenges involves greater professional training and involvement in relation to intersubjectivity, interaction, openness (12), the application of bioethics (13), as well as recognition of the institutional context in which health care is produced, with its claims, norms and demands (14).

In this line, it is important to ask how is the training of medical geneticists in Colombia? To try to answer this question, it is necessary to point out that the doctor-patient relationship and genetic counseling are fundamental components of clinical genetics. However, in Colombia, training in genetic counseling as an independent discipline does not exist (15). In our context, it is clinical geneticists who must fulfill this function, but in the country, as in the rest of Latin American countries, training in clinical genetics has been limited (15, 16), due to the small number of programs existing.

In the case of orphan diseases, the clinical and communication skills of medical geneticists are required in all types of consultations, both to deliver the diagnosis of the orphan disease, and when announcing the non-existence of curative treatments for the diagnosed disease. This situation represents a complexity, since the average time to reach a final diagnosis can vary from five to ten years and require reviews by more than ten doctors (16, p. 371), which translates into a fracture of the bonds of trust and respect on which the doctor-patient relationship rests (13).

In this context, the results of this research revealed differences in the clinical and communication skills of geneticists to meet the psychosocial needs of patients and their caregivers, that is, to address the feelings and emotions generated in the consultation, even when they have postgraduate specialties and years of practice experience. These results show that managing these situations is a complex task that involves personal aspects of the doctor (17).

On the other hand, the influence of the biomedical and scientific nature in the post-gradual training of professionals in this research may also explain the limitation in addressing psychosocial factors. As a scientific discipline, clinical genetics combines concepts, knowledge, and techniques that help you recognize different orphan diseases by the combination of their clinical manifestations. However, the attitudes of the doctors, in the face of the presence of a bodily deficiency in the patients, indicated the influence of the hegemonic perspective in their gaze, with an interpretation of incapacity and inferiority (18), which annulled the word and image .

Although the patients in the genetic consultations observed are people with diagnoses of orphan diseases that can generate certain functional limitations, it is necessary to state that, above all, they are dignified human beings with rights. In this regard, it is necessary to think about the necessary consideration of bodies, feelings and affections in medical practice, even when the nature of the observed pediatric consultation involves the participation of a caregiver as a mediator for the dialogue with the geneticist doctor.

Thus, addressing this discrepancy between the needs of the patient-caregiver dyad and the reality of the consultation requires that the physician be able to combine scientific knowledge and the subjective demands raised by other actors (12). In other words, their daily professional practices require strengthening and transcending technical skills to give space to a reflective dimension that allows them to critically analyze the ethical and political nature of their technical position (19), the complexity of the situations to be addressed, and provide the necessary support. and pertinent according to the particularity of the case and generate an integral well-being in people. However, and as Pérez-Rancel (2000) puts it, some professionals, among them doctors, who have undergraduate training in basic sciences, reinforced in postgraduate studies, have consolidated a social representation of science that is far from this way of understanding and addressing realities (20).

Another important challenge has to do with the fact that the geneticist doctor must not only face the burden that the patient and his caregiver bring due to the experience of the genetic condition, but also due to the difficulties that a health system that the doctor represents represents. for such attention to be carried out. Therefore, one of the challenges of the first meeting between the geneticist, the patient and his caregiver is the mediation of those personal conditions (ideas, perceptions, interests and expectations) and contextual conditions (trajectory and standardization of the system) that predispose the relationship.

In particular, in this observation exercise, the institutional framework of the clinic was another challenge for the geneticist. In this research, two pediatric clinical genetics consultations stand out, which represented positive experiences regarding patient care derived from the autonomy and flexibility that doctors manifested in their professional practice. Specifically, the extension of attention times according to the type of consultation, made it possible to listen and build a bond with the patient. However, this is not a common situation for people who make use of the Colombian health system, since the above is possible in the institutional context of this study, that is, a highly complex private health institution, in which Medical geneticists with clinical experience participate, which allows them to establish their own criteria on care, above what is standardized or established by the system (21).

5. Conclusions

- The research carried out allowed a first approximation to the clinical genetics consultation, in a high level of complexity institution in the city of Cali. Here it was evidenced that one of the most important challenges that the doctor assumes in this consultation is located in the relationship established with the patients and their companions, a relationship that is crossed by internal and external factors to the consultation.
- Although there is no "ideal" way to relate to the patient and/or family member (22) in the consultation, it is trusted that the doctor has the ability to understand the situation, signify the experience and know what to do (12). In this sense, it is possible to conclude that the foundations of a good relationship, perhaps, are found in the simple act of listening and identifying the need/desire that both companions and patients present in each situation. In other words, in establishing a relationship that is as horizontal as possible, based on listening and trust, a relationship in which all parties have a voice.
- It is necessary to train doctors, in general, and clinical geneticists in particular, on the approach to psychosocial factors internal and external to the genetics consultation, from undergraduate, postgraduate and continuing education programs, with the aim of Immediately support patients and caregivers, without having to wait and delegate these functions to a professional in psychology, since this can generate a fragmentation of care, more administrative procedures, time and travel for the patient and their companion.
- Research on the understanding of the interactions that arise or may arise between the doctor-patient-caregiver triad and the events that can influence such interaction, require further monitoring, both in Colombia and in all places where genetics is practiced. clinic. This article begins a small reflection on the experiences of two geneticists linked to a private health institution. Although the findings presented are comparable to similar clinical settings, they cannot be generalized. To confirm it and to know particularities, it is necessary to carry out more studies. We believe that future research should delve into some of the issues that we address here with larger groups of geneticists, patients, and caregivers.
- The application of a qualitative methodology, in which the lived experiences of the geneticists doctors in the consultation and the relationships established in them were given, allowed to investigate and learn about issues of the psychosocial field that are not possible to address from of structured methodologies that limit the generation of trust and openness to the subject. On the contrary, the narrative methodology allowed us to examine relevant data from the clinical practice, in an environment considered spontaneous. This is related to what Lopera Vásquez

(2020) stated when he stated that to inquire about some issues, such as those in which subjectivity occurs, structured instruments are of little use (23).

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