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Como contornar o impacto das doenças genéticas na vida dos pacientes e seus familiares?

How to overcome the impact of genetic diseases on the lives of patients and their families?

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RESUMO

Introdução: As doenças genéticas raras trazem desafios quanto a seu diagnóstico e tratamento. Muitos de seus sintomas são similares aos de doenças comuns, o que tende a atrasar o diagnóstico correto. Desse modo, o descobrimento e tratamento adequado da doença costuma decorrer de processo longo, cansativo e oneroso, gerando impactos psicoemocionais a todos os envolvidos.

Objetivo: Revisar o impacto psicoemocional sofrido pelos afetados e seus familiares por doenças genéticas raras durante o processo saúde-doença.

Método: Trata-se de revisão narrativa empregando artigos em português e inglês obtidos por meio de plataformas virtuais de pesquisa através dos descritores: "doenças raras", "doenças genéticas", "estresse psicológico", "tratamento" e "diagnóstico".

Resultados: Utilizou-se 20 artigos, sendo eles lidos e resumidos. Foram utilizados artigos publicados entre 2000 a 2024.

Conclusão: Considerar os impactos emocionais, caracterizados pela tristeza, ansiedade e frustração, desencadeados pelos desafios rumo ao diagnóstico e tratamento de doenças genéticas raras é essencial ao atendimento íntegro e adequado ao paciente.

PALAVRAS-CHAVE: Doenças genéticas raras. Impacto psicoemocional. Diagnóstico. Tratamento.

ABSTRACT

Introduction: Rare genetic diseases pose challenges in terms of diagnosis and treatment. Many of their symptoms are similar to those of common diseases, which tends to delay correct diagnosis. Thus, the discovery and appropriate treatment of the disease usually involves a long, tiring and costly process, generating psycho-emotional impacts for all involved.

Objective: To review the psycho-emotional impact suffered by those affected and their families by rare genetic diseases during the health-disease process.

Method: This is a narrative review using articles in Portuguese and English obtained through virtual research platforms using the descriptors: "rare diseases", "genetic diseases", "psychological stress", "treatment" and "diagnosis".

Results: Twenty-one articles were used, which were read and summarized. Articles published between 2000 and 2024 were used.

Conclusion: Considering the emotional impacts, characterized by sadness, anxiety and frustration, triggered by the challenges towards the diagnosis and treatment of rare genetic diseases is essential for comprehensive and appropriate patient care.

KEYWORDS: Rare genetic diseases. Psycho-emotional impact. Diagnosis. Treatment.

Central message

The necessary care with the impact of genetic diseases on the lives of patients and their families does not consist only of the treatment of their rare condition, but also of psychological attention, since the "odyssey" in search of the diagnosis generates considerable mental and emotional exhaustion, both for them and for their families.

Perspective

It is evident the need not only for the treatment of rare genetic diseases so that their carriers can be inserted into society and overcome their social difficulties, but also for psychological monitoring of patients and their families so that they are able to face the difficulties and challenges arising from the condition and the non-acceptance of the individual by society.

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INTRODUCTION

Genetic diseases are conditions inherited or caused by mutations again in certain genes throughout life. They are usually challenging in terms of their diagnosis and treatment due to their complexity and about 80% of them are considered rare diseases, characterized by affecting 1.3 people per 2000 individuals. These diseases are usually difficult to diagnose, as they manifest symptoms similar to those of common diseases and can be multisystemic, causing doubts in doctors about the diagnostic hypothesis and leading to mistaken treatments. In addition, many health professionals do not have sufficient mastery and knowledge about rare genetic conditions, aggravating the situation. In this way, several patients receive late diagnoses, after traveling a long and costly journey, full of excessive and unnecessary consultations and exams in search of treatment for their condition. There are cases in which the disease caused irreversible damage to the affected person due to the delay in treatment.[1-5]

In this sense, the necessary care does not consist only of the treatment of his rare condition, but also of psychological attention, since the "odyssey" in search of the diagnosis generates considerable mental and emotional exhaustion, both for him and for his family.[6-8]

In this situation, the most common feelings manifested by affected individuals and their families are anguish, stress and despair, motivated by uncertainty and distress about the disease and its future. The lack of answers about the health condition, its possible worsening, the logistical and bureaucratic challenges to obtain treatment and diagnosis are factors that corroborate the psychoemotional suffering of both the patient and his family, not to mention the social stigma associated with rare diseases.[9]

In Brazil, although genetic testing and post-diagnosis follow-up are offered free of charge by the SUS through the National Policy for Comprehensive Care for People with Rare Diseases (PNAIPDR), many people still face the physical consequences and mental exhaustion resulting from the diagnosis. This is due to numerous factors, such as the population's lack of knowledge about these policies and genetic conditions, and there is also the difficulty of access to specialized centers for rare diseases, concentrated mainly in the South and Southeast regions of the country, which forces citizens to migrate in search of adequate care. In addition, the misinformation of many health professionals about rare genetic diseases makes it difficult for them to diagnose them accurately. These factors, in addition to postponing the treatment of the affected person, impair their quality of life and prolong the impairment of their health.[6,8,10]

As for the social stigma faced by those affected, social exclusion and ableism stand out. These prejudices are aggravated when the condition severely affects the individual's phenotype or motor, neurological or behavioral skills, as they evidence their condition. Thus, cases of bullying against students with genetic conditions in schools are not rare, forcing them to migrate to special institutions, due to the lack of an adequate inclusion program, even if they have the mental and physical condition to follow classes in regular schools. Such prejudice extends to the professional sphere, with situations occurring in which differentiated treatments, whose objective is to help the patient, become ableist when they show low expectations regarding the patient's abilities or potential, or even when the necessary help does not exist due to the negligence of the leaders or those responsible. Thus, by being seen as inferior and incapable by society and having their disease as a source of prejudice and discrimination, those affected by rare genetic diseases feel helpless and disillusioned, which negatively affects their health-disease process.[11,12]

Therefore, aiming at effective treatment, improvement in the quality of life of carriers of rare genetic diseases, and the optimization of the search for diagnosis, it is necessary to overcome logistical and infrastructural clashes and social and medical misinformation. However, there is also a demand for psychological attention to treat the traumas, stress and sadness generated during the odyssey traveled towards adequate medical care, characterized by challenges of social inclusion and physical and mental exhaustion.

Thus, this study aimed to review the psychoemotional impact suffered by those affected by rare genetic diseases during the health-disease process, highlighting the importance of considering these aspects so that the integral treatment, symptomatic aspects of the disease and its mental and emotional consequences, are provided to these individuals.

METHOD

This is a narrative review of the literature consisting of review articles and case reports from 2000 to 2024, in Portuguese and English. In the search for articles pertinent to the theme and appropriate to the study, the Scielo, PubMed, Google Scholar and Capes Periódicos databases were consulted, through the application of the following descriptors: rare diseases, genetic diseases, psychological stress, treatment and diagnosis, resulting in 20 articles that were used in this study.

DISCUSSION

Genetic diseases

Genetic diseases can be inherited or result from de novo mutations, and can be congenital or developed throughout the individual's life. Such clinical conditions manifest themselves as physical, mental or sensory defects, and, therefore, tend to alter the quality of life of the affected person and bring daily complications to him. These diseases can be classified as monogenic, chromosomal, mitochondrial, complex,

and multifactorial.[1,3,5,13]

About 80% of genetic diseases are hereditary, and the risk of a child being born with a genetic alteration is higher when the family has a family history of a genetic disorder, when the parents already have a child with the characteristic or in consanguineous unions.[2,7]

These conditions can also arise due to environmental influences, as some factors related to the quality of life of individuals can contribute to the occurrence of genetic mutations, especially somatic ones. For example, contact with substances that are harmful to health, such as radiation, chemotherapy drugs, and chemical pollutants, increases the risk of spontaneous mutations in genes housekeeping, that is, maintenance and control of the organism as a whole. Therefore, it is important to maintain a good quality of life for the body to function well, and to prevent not only genetic diseases, but also acquired ones.[14]

The WHO (World Health Organization) estimates that the number of individuals affected by a rare genetic disease is 1.3 people per 2,000, which would correspond to approximately 300 million people in the world, with between 6 and 7 thousand different genetic diseases.[8] According to data from the Ministry of Health, in Brazil this number is about 13 million people affected. Still, only 10% of these diseases have specific treatment, often at a high cost.[3,7]

Although there is a large number of people affected by rare genetic diseases, most of the scientific literature concentrates studies on approximately 113 diseases, considering that these conditions still receive little attention in the psychosocial sphere, with limited literature on their psychosocial influence on the individual's life.[7,15]

Difficulties in diagnosing rare genetic diseases

Diagnosing genetic diseases is challenging for the medical field, as it is often difficult to know which condition is affecting the person, given that some of its symptoms are similar to the symptoms of common diseases. Genetic consultations with specialists, prenatal tests, and specific genetic tests on the patient and their family members, affected or not, can help prevent, understand, and identify possible genetic diseases. If pathogenic and/or likely pathogenic variants are in genes that encode proteins and enzymes involved in important biochemical pathways or lead to changes in brain structure, ancillary laboratory and imaging tests can be performed at diagnosis. However, if these are not available, the diagnosis ends up being completely clinical, without confirmation through complementary tests.[2,3] Genetic counseling is another practice that can help and inform people about genetic diseases. For this, professionals need adequate information to guide patients about the risks of recurrence and how these diseases are transmitted. This consultation is usually indicated for people who have a history of neurological or degenerative diseases, a personal or family history of cancer and in cases of repeated miscarriage and infertility.[1]

In addition, preimplantation genetic diagnosis can also be a way to diagnose genetic diseases in cases of pregnancies with risk factors, such as advanced maternal age, family history of a genetic disease or consanguinity. This test is performed on embryos generated for in vitro fertilization before they are implanted in the uterus, making it possible to select the most viable embryos without mutations in genes that could compromise the health of the fetus. Thus, it is a technique that allows the diagnosis of various genetic diseases, but its cost is very high, making it inaccessible to a large portion of the population. In Brazil, this test is regulated by the Federal Council of Medicine, but there are still debates about its ethical implications, due to the disposal of embryos.[16,17]

When the disease is rare, several challenges arise due to the lack or difficulty of access to specialized professionals, resources, treatment and information. In these situations, the most frequent feelings in families are that of impotence, anguish and revolt. Also, the misinformation and frustration generated create mistaken expectations about the disease, which interferes with adequate adherence to treatment and the search for diagnosis.[8] On the path to diagnosis, excessive and unnecessary tests are often requested, as well as incorrect diagnoses and inefficient treatment are provided, generating even more stress for the patient and their families.[10]

Thus, the delay in obtaining the diagnosis generates strong feelings of despair, stress and confusion, which requires psychological treatment from both the patient and their families.[9]

In these cases where the diagnosis takes a long time to be reached, or even is not, the affected person tends to lose hope in his health and resigns himself to the fact that his situation may not change. The main impacts suffered by patients can be divided into psychological impacts, social implications, and functional impacts, which worsen as diagnosis and treatment become delayed.[10]

In Brazil, there are no specialized services in genetic health in all parts of the territory, forcing those living in smaller cities to travel to large centers to obtain access to specialists and a better medical-hospital structure for treatment. For those individuals without human and financial resources, such a displacement is usually unfeasible and, when executed, time-consuming and loaded with logistical challenges and financial difficulties. In the absence of adequate professionals, the diagnosis is often mistaken or the disease is neglected. In addition, due to the long waiting time, contact with specialists is often made after the damage caused by the disease is already irreversible or when it is in an advanced stage, generating a worse prognosis.[7,8]

Challenges in the treatment of rare genetic diseases

The treatments of genetic diseases vary according to their manifestations. However, there are drugs,

especially intended for the treatment and/or control of certain rare genetic diseases, whose costs are high and are not yet included in the list of exceptional drugs through judicial measures, making it difficult for the general population to access them. Also, rare genetic diseases usually require costly exams and numerous consultations with different professionals, generating a long journey from diagnosis to treatment.[6]

Therefore, the treatment of rare genetic diseases is a challenge aggravated by practical-relational and bureaucratic-institutional problems.[3] When diseases are rare, high-cost drugs are associated with orphan drugs, so called, because they are usually not developed by pharmaceutical industries due to economic reasons and low demand and profit potential. In developing or underdeveloped countries, even if there are people with rare genetic conditions, many of these people are unable to afford the drugs due to their high cost. This causes many patients to resort to judicialization as a way to gain access to them. However, there are uncertainties as to whether or not the medication will be released. Many doctors do not consider judicialization the best option and claim that it stigmatizes patients as "a problem patient for the State".[3,18]

In Brazil, aiming to solve this problem, there is the National Policy for Comprehensive Care for People with Rare Diseases (PNAIPDR), which provides funding for reference centers so that genetic tests can be carried out in them and that they can offer medicines and genetic counseling to people who need them, free of charge, through the SUS. Its guidelines provide primary health care (PHC) actions, covering early diagnosis and genetic mapping for people with risk factors and suspicious situations, as well as post-diagnosis clinical follow-up and care when necessary.[8] However, not all those affected can access this policy, which may not be as effective in practice as in theory.

In addition, further raising costs, the treatment of a genetic condition usually requires the monitoring of professionals other than the doctor, such as physiotherapists, speech therapists and psychologists, to try to alleviate the symptoms of the disease and slow its progress.

Another problem that hinders the diagnosis and treatment of genetic diseases is the fact that in Brazil there are few geneticists. Thus, the number of professionals is insufficient and most patients do not receive adequate attention and care. It is also noteworthy that most genetics services are concentrated in the South and Southeast regions of the country. This centralization of services causes the migration of many people to different regions in search of treatment. Often these families end up having to quit their jobs and reorganize their life in the city due to the treatment of the affected family member.[8]

A study funded by the Wellcome Trust in Brazil, a British institution that promotes scientific research in several areas, showed that patients often face a long and tortuous path to reach the final diagnosis. The health professionals interviewed during the study pointed out the lack of information about rare genetic diseases on the part of primary care professionals with a barrier to diagnosis. Due to this factor, many professionals feel insecure in prescribing medications, fearing the worsening of the disease. It is noteworthy that the explanation about the disease tends to help the family in the information process, while misinformation impairs adherence to treatment and corroborates the patient's social isolation, due to insecurities.[6] This study also showed that the lack of access to the services of specialists in SUS genetics and the itinerary taken to reach the final diagnosis of the disease, consisting of several tests and many consultations, corroborates erroneous and late diagnoses, causing the disease to advance due to lack of treatment or inadequate treatments. These consultations are often carried out in the private network due to lack of option, generating several extra costs, which can harm people's routines, especially the low-income population. In addition, even though SUS guidelines provide for multiprofessional care for those affected by genetic diseases, access to these professionals remains precarious and there is a long wait, due to the lack of material and human resources.[6]

Those patients who have experienced late diagnosis are affected by great psychological trauma. This is due to the exhaustion caused by constant consultations with different specialists, who do not reach effective conclusions or guide inappropriate treatments, further damaging their health. Thus, feelings of frustration, anxiety, low self-esteem, shame about their condition (especially in cases where the symptoms of the disease affect the physical appearance of the affected person) and insecurity are very present in their lives. These, without a diagnosis, only know that they are sick, which tends to generate a pessimistic view of life and impairs their long-term planning. Such feelings also negatively affect the social interactions of those affected, making it difficult to maintain healthy relationships and access professional and educational opportunities. Also, with the delay in diagnosis, there is an increase in the lack of credibility in medicine; Thus, several individuals and/or family members turn to alternative sources and without scientifically proven information in search of answers.[10]

Impact of genetic diseases on the daily lives of patients and their guardians

With rare genetic diseases, family members deal with new challenges when faced with treatment and lifestyle changes due to the disease. Those affected need treatments and interventions throughout their lives. This affects their relationships with friends and family, causes the deprivation of certain activities as a result of complications of the disease or the lack of time generated by medical commitments, which corroborates the suffering of mental health. Adaptation is made even more difficult in cases where

the disease causes pain, high risk of life, sensory and/or motor losses or when it includes invasive treatments that strongly affect their routine.[11]

Doctors usually see the mother figure as the protagonist of the pain of having a child who suffers from some genetic disease; the mothers of these children are idealized as people who put their lives aside to dedicate themselves to these children. In this way, many responsibilities are directed to the mother, and the woman may end up feeling pressured when having to deal with everything related to her children. In addition, this material and affective overload can end up generating tensions and emotional and physical problems for her. Another consequence of this exclusive dedication to the affected child is the impossibility of performing various activities, including leisure activities. Depending on the disease, the child needs constant care, and without being able to divide time between work and children, many mothers end up giving up their professional and personal lives, and over time, they may end up suffering physically and emotionally.[10]

Also, after the diagnosis of the disease, although the feeling of relief commonly occurs, many parents blame themselves for their children's diseases, which generates anguish and hinders the health-disease process for the family.[10]

In this perspective, the importance of the doctor informing the family about the condition, forms of transmission and risks of recurrence is emphasized. It is essential for the professional to highlight to the patient and his family that the presence of a genetic disease, even if it is hereditary, is not due to the parents, family members or even the affected person, also emphasizing the existence of other factors that corroborate the development of these diseases.[1]

In cases of high risk of life, families tend to adopt two distinct behaviors: overprotection or negligence. The first is due to the child's perception of fragility and the search to meet all their needs, something that sometimes occurs in an exacerbated way, further limiting their autonomy. The second occurs in an attempt to reduce affective involvement in the event of death, to avoid great suffering.[11]

The invisibility of the patient mentioned above does not only occur in the family sphere, but also in the medical and social sphere. Some professionals may end up having a limited view of the patient by focusing only on their condition and complexity, leaving aside the patient as an individual who needs clarification, has pain and feelings. In addition, the immersion of these individuals in society can be very difficult. There are many limits placed by diseases, whether physical, mental, understanding and the ability to interact socially. Society tends to look at these people differently, as if these individuals were victims of something very bad, leading to a process of discrimination. There are also those whose view of those affected is of inferior people and incapable of performing various jobs, something that emotionally affects both the patient and his family.[12,13]

Still regarding the inclusion of rare disease patients in society, even if they are physically "included" in the communities, they usually remain intellectually segregated. This situation is evident in schools, where the integration of those affected does not occur due to the lack of teacher training and the absence of school support professionals trained in inclusion. Inclusion in most schools is utopian, as the work done by professionals tends more towards ableism, leading to segregation or even exclusion. For this reason, many children with genetic diseases, even with conditions to follow the education in ordinary institutions, go to study in special schools, something that contributes to the feeling of exclusion experienced by those with genetic diseases. Although some children enjoy the time spent in these schools, from a certain age they become aware of the social stigma and the reason for being in that institution. They soon become hesitant about others' views of their school and their medical condition and how it will affect their life in society.[14]

When these people attend normal schools, they are often easy targets for bullying and exclusion, due to the stigma of society-imposed standards of "normality," especially when professionals and classmates do not understand their condition and do not recognize the importance of acceptance and mutual respect. This social isolation is greatly aggravated when the disease generates symptoms that affect the carrier's physical appearance or motor skills, such as wounds or speech difficulties.[11]

Without the support of society in general, religions and cults tend to be a support network for those affected. Todd[14], in 2021, studied the relationship between religions and the behavior of patients, doctors, and families. The values preached can serve as an incentive for the individual to persist in the fight against his disease, for the doctor not to give up on the patient, for the families to continue to support the affected family member and for the others to develop a sense of empathy and compassion. Also according to Todd, another action generated by religion are initiatives to help the sick, such as campaigns to collect donations and funds to pay for treatment. Furthermore, the ideals of valuing life present in various beliefs serve as an encouragement to professionals, patients and society to persist in the fight against diseases and for the appropriate treatment of those affected.[14]

CONCLUSION

Rare genetic diseases have several implications for those affected and their families, with the main impacts being psychological (anxiety, fear, uncertainty), functional (loss of independence, limitations generated by the disease, reduction of academic and professional opportunities) and social (social exclusion, low socialization capacity). These are aggravated when the diagnosis is late, which favors the progression of the disease and the loss of hope of the individual and his family, which generates feelings of resignation, revolt and shame. Thus, it

becomes evident the need not only for the treatment of rare genetic diseases so that their carriers can be inserted into society and overcome their social difficulties, but also for psychological monitoring of patients and their families so that they are able to face the difficulties and challenges arising from the condition and the non-acceptance of the individual by society.

Authors' contributions

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Cornélio Schwambach: Methodology, Writing (original draft), Writing (review and editing)
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REFERENCES

1. De Pina-Neto JM. Genetic counseling. J Pediatr (Rio J). 2008;84(4 Suppl):20-6. http://doi.org/10.2223/JPED.1782
2. Kaisermann J. Classificação de doenças genéticas. Yavor Mendel - Google Livros. 2019. Available from: https://books.google.com.br/books?hl=pt-BR&lr=&id=5AuyDwAAQBAJ&oi=fnd&pg=PT2&dq=tipos+de+doenças+genéticas&ots=0pWYZ_GVCm&sig=WLaqGKKysfn2pBMcydaz8OrBogM#v=onepage&q=tipos de doenças genéticas&f=false
3. Iriart JAB, Nucci MF, Muniz TP, Viana GB, Aureliano W de A, Gibbon S. Da busca pelo diagnóstico às incertezas do tratamento: desafios do cuidado para as doenças genéticas raras no Brasil. Cien Saude Colet. 2019;24(10):3637-50. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232019001003637&tlng=pt
4. Finegold DN. Defeitos de um único gene - Tópicos especiais - Manuais MSD edição para profissionais. 2019. Available from: https://www.msdmanuals.com/pt-br/profissional/tópicos-especiais/princípios-gerais-da-genética-médica/defeitos-de-um-único-gene
5. Nogueira C, Vilarinho L. Doenças mitocondriais: síndrome da depleção do mtDNA. Observações - Boletim Epidemiológico. 2016:25-8.
6. Micheletto MRD, do Amaral VLAR, Valerio NI, Fett-Conte AC. Adesão ao tratamento após aconselhamento genético na síndrome de down. Psicol em Estud. 2009;14(3):491-500.
7. De Souza ÍP, Androlage JS, Bellato R, Barsaglini RA. A qualitative approach to rare genetic diseases: An integrative review of the national and international literature. Cienc e Saude Coletiva. 2019;24(10):3683-700. https://doi.org/10.1590/1413-8123201824410.17822019
8. Dos Santos CS, Kishi RGB, da Costa DLG, da Silva DSD, Narciso TRF, de Avó LR da S, et al. Identificação de doenças genéticas na Atenção Primária à Saúde: experiência de um município de porte médio no Brasil. Rev bras med fam comunidade. 2020; 15(42):2347. https://doi.org/10.5712/rbmfc15(42)2347
9. Stone KJ. Psychological Support at Diagnosis of a Rare Disease. 2022. Available from: https://rd-rp.com/wp-content/uploads/2022/03/220202-Literature-Review-Report.pdf
10. Benito-Lozano J, Arias-Merino G, Gómez-Martínez M, Arconada-López B, Ruiz-García B, de la Paz MP, et al. Psychosocial impact at the time of a rare disease diagnosis. PLoS One. 2023;18(7 July):1-17. https://doi.org/10.1371/journal.pone.0288875
11. Da Silva ACS. Impacto da doença crônica infantil sobre a saúde mental de cuidadores primários e o desenvolvimento socioemocional da criança. 2018:1-118.
12. Martins AJ, Cardoso MHC de A, Llerena-Júnior JC, Moreira MCN. A concepção de família e religiosidade presente nos discursos produzidos por profissionais médicos acerca de crianças com doenças genéticas. Ciência e Saúde Coletiva. 2012;17(2):545-53. https://doi.org/10.1590/S1413-81232012000200027
13. Jain SV, Murrell DF. Psychosocial impact of inherited and autoimmune blistering diseases. Int J Women's Dermatology. 2018;4(1):49-53. https://doi.org/10.1016/j.ijwd.2017.11.04
14. Todd S. Working in the public and private domains: Staff management of community activities for and the identities of people with intellectual disability. Intellect Disabil Res. 2000;44(5):600-20. https://doi.org/10.1046/j.1365-2788.2000.00281.x