DIMENSIONS OF SOCIAL INCLUSION IN THE CONTEXT OF VISUAL IMPAIRMENT: A CASE STUDY ON LEBER'S HEREDITARY OPTIC NEUROPATHY

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Abstract: *The paper explores the social inclusion of people with visual impairment, namely, Leber's hereditary optic neuropathy, which is a rare condition, the prevalence being one in 50,000 people. The paper is developed around the case study and highlights the challenges and difficulties experienced by a healthy person who is suddenly diagnosed at the age of 20 with Leber's hereditary optic neuropathy. The research uses the qualitative method, and the practical implications are aimed at reducing the psycho-emotional difficulties of people with visual impairments, early recognition of symptoms and promoting social equity and inclusion.*

Keywords: *Leber's hereditary optic neuropathy; psychological challenges; inclusion; stigmatization; case study.*

Introduction

Article „Dimensions of social inclusion in the context of visual impairment: A case study on Leber's Hereditary Optic Neuropathy" focuses on promoting equity and social inclusion among individuals with visual impairments, specifically those diagnosed with Leber's hereditary optic neuropathy (LHON).

Interdisciplinary and intersectoral approaches in social work emphasize social inclusion, and Leber's optic neuropathy presents a rare case study, as the estimated prevalence of this condition is 1 in 50,000 people. The article discusses the challenges and difficulties encountered by an individual who, up until the age of 20, was healthy but was suddenly diagnosed with Leber's hereditary optic neuropathy, leading to a dramatic change in their life.

The case study highlights psycho-emotional difficulties, stigmatization, discrimination, and the specific responses from friends, family, and both public and private institutions. The study is relevant for a better understanding of the issues faced by individuals with visual impairments and aims to foster respect, empathy, and the role of social work in improving the quality of life for vulnerable groups.

Additionally, the article explores the positive aspects of the diagnosis as a bridge between disability and ability. In this regard, Leber's hereditary optic neuropathy is analyzed from multiple perspectives to enhance its application in the education and professional training of social workers.

The World Health Organization's 2019 World Report on Vision states that 2.2 billion people face vision impairments. The loss of autonomy represents a significant issue, as spatial orientation, environmental perception, clear understanding of location, and the ability to navigate are all hindered due to the presence of visual impairment.

Mustață (2019) highlights the connection between hereditary conditions, such as optic neuropathy, and the manifestation of anxiety in an individual’s life. The author notes that affected patients may also experience heart problems associated with anxiety and hereditary optic neuropathy. Social support is identified as the main factor in managing anxiety, as interaction with close individuals or medical professionals helps reduce anxiety by allowing fears related to the difficult situation to be expressed. Social support is a factor that decreases the level of depression and indicates higher treatment adherence; thus, we can deduce the role and necessity of an extended support group.

Roșca (2015) emphasizes that devices such as computers and emerging technologies are among the most frequently utilized tools by individuals with visual impairments. Although assistive technologies significantly facilitate socio-professional integration, their high cost remains a major barrier. The financial burden associated with such tools is substantial, with prices ranging from approximately $100 for a basic scanner to $7,000 for a Braille printer. Consequently, many individuals with disabilities are unable to access these technologies, which exacerbates existing social and economic inequalities.

Phillips & Proulx (2018) state that social interaction involves observing gestures, attitudes, and non-verbal language—elements that are inaccessible to individuals with visual impairments. This inaccessibility often leads to frustration and social isolation. Sîrbu and Măligă (2015) studied the psychological aspects of individuals with visual impairments. Visual impairment can lead to feelings of inferiority, negative emotional states, depression, and anxiety, all of which negatively impact the emotional domain. The total or partial loss of visual capacity often results in financial instability due to the loss of work ability, as well as a decline in social status caused by discrimination, the loss of support groups, and a decrease in personal independence.

Racu and Maximciuc (2018) state that social inclusion of individuals with visual impairments gradually declines when society instills the belief that such individuals are helpless, pitiable, limited in abilities, and incapable. Social prejudice causes stress as well as psychological and emotional suffering. The authors view disability more as a social construct than a purely medical condition. Therefore, recovery requires a change in society's attitudes and perceptions rather than a change in the individual's medical state itself.

Popovici (2015) states that psychological and emotional issues arise due to the stress caused by visual impairment. Stress influences the reactions of individuals with visual impairments, and decreased motivation for activity is one of its consequences. Stress is a characteristic of contemporary life, stemming from rapid change. Individuals are unable to quickly adapt to new survival conditions. Harmful environmental influences, combined with those specifically related to visual impairment, contribute to the emergence of what is known as stress. The more affected a person is by their diagnosis, the more deeply they become aware of their own adaptation challenges.

Cebotaru & Cebotaru (2018) argue that there are prejudices based solely on disability. Employers may hold preconceptions and stereotypes regarding the efficiency of employees with disabilities, the lack of positions compatible with the individual's qualifications, fear of being unable to dismiss an employee with a disability due to legal regulations, fear of creating conflicts among employees, and prejudices suggesting that individuals with visual impairments are not as well-prepared or qualified to be integrated into the labor market.

Jackson et al., (2019) investigated the emotional state of individuals with visual impairments and concluded that they are at a higher risk of experiencing discrimination, depression, anxiety, psychiatric distress, and reduced mental well-being. The researchers showed that people with visual impairments tend to have poorer mental health compared to the general population. Reduced social contact and feelings of loneliness are factors that contribute to increased anxiety and depression. The association between visual impairment and lower life satisfaction is scientifically supported, with some evidence suggesting that vision loss is linked to the onset of depression.

La Morgia et al., (2024) state that Leber Hereditary Optic Neuropathy (LHON) typically manifests in adulthood and only rarely at birth or during childhood. Patients are often misdiagnosed, which leads to delays in initiating appropriate treatment. According to Carelli et al. (2023), the most critical aspect of the disease is timely diagnosis, as treatment must begin promptly due to the condition affecting the optic nerve. LHON is maternally inherited, and its main clinical feature is the sudden, painless loss of vision over a short period of time.

Mackey et al., (2025) state that Leber Hereditary Optic Neuropathy (LHON) affects vision and ultimately leads to vision loss. When considering any condition that results in vision loss, it becomes evident that such an outcome has a devastating impact on the life of the diagnosed individual, with social and professional adaptation requiring time and patience. Individuals facing LHON need counseling and emotional support to cope with the trauma associated with the condition.

According to Watson et al., (2023), from a medical standpoint, vision loss following an LHON diagnosis is to be expected; however, affected individuals require comprehensive support across all domains. Those left with low vision need assistive technologies tailored to their needs in order to overcome daily challenges and continue living independently. Moreover, state support is essential in helping them develop the skills and competencies necessary to function autonomously.

Von Graefe (1858) noted that the diagnosis of Leber Hereditary Optic Neuropathy (LHON) is most frequently observed in young males. Wallace et al., (1998) discovered that the mutation associated with LHON is linked to the maternal gene. In many cases, individuals may carry the pathogenic variant without developing symptoms, or symptom onset may be delayed or absent altogether.

According to Pandya et al., (2024), the clinical hallmark of the disease is a painless, sudden loss of vision in one eye, followed shortly by the second eye, typically within a few weeks to one year. Stramkauskaitė, et al. (2022) report that most cases of disease onset occur between the ages of 15 and 35, with a higher prevalence among males. Specifically, the average age of symptom onset is 25 years for males and 30 years for females.

Kearns et al., (2025) discussed Leber Hereditary Optic Neuropathy (LHON) and highlighted the main challenges and difficulties experienced by individuals diagnosed with the condition. Vision loss significantly hinders personal and professional development; reading, interacting, socializing, recognizing people, and driving become major obstacles. Chen et al., (2022) note that treatment options remain limited, with no conclusive evidence of symptom resolution. Thus, the authors emphasize that the primary needs of individuals diagnosed with LHON involve identifying suitable professions that support autonomy and independence, as well as focusing on personal development in their current situation. According to the authors, this is the only intervention with long-term effects for individuals with LHON.

Hage et al., (2021) argue that advancements in technology contribute to a more independent life for LHON patients. In cases of vision loss, newly developed self-driving cars, various reading-assistive software, smartphones, and applications can support individuals in their daily tasks and responsibilities, leading to greater autonomy. However, it is also noted that such smart technologies often involve high costs.

Bušányová et al., (2024) state that the sudden loss of vision represents a life-altering event that profoundly impacts both future experiences and present emotional states. For individuals who possess a driver's license, vision loss renders them unable to drive, often resulting in a perceived loss of independence and autonomy.

From a psychological perspective, affected individuals may experience loneliness and social isolation, as they are no longer able to read signs or move around independently. Emotional well-being, psychological health, interpersonal relationships, and leisure activities—all these aspects of life are significantly affected following the onset of vision loss.

An imprecise language in the field of social work can create confusion, and people with disabilities are much more vulnerable to misunderstandings and discrimination. In this sense, individuals with disabilities interpret words in a dual way, as these can either act as facilitators of social inclusion or become terms that generate stigmatization. (Goian, 2010)

Moreover, in the educational context, Goian (2020) points out that bullying can even stem from a disability, which should instead generate empathy and involvement, not barriers. Consequently, bullying situations experienced by children with disabilities can lower their self-esteem, and the social worker's role is to act as a mediator.

In 2013, Goian conducted research focused on the social work system in the Banat region and highlighted existing shortcomings that can affect vulnerable groups, including persons with disabilities. This emphasizes the importance of the professional integration of specialized staff in the field, as well as the urgent need for adequate funding. Moreover, in this context, it becomes clear that services dedicated to persons with disabilities must be strengthened, thereby supporting equal access to rights and facilitating their social and professional integration.

Leber Hereditary Optic Neuropathy (LHON) is a rare maternally inherited disease, with symptoms appearing unpredictably; some individuals carrying the mutation may remain asymptomatic throughout their lives. As emphasized in the specialized literature, accurate, efficient, and early diagnosis represents the primary chance of preserving vision.

The later the diagnosis is made, the lower the chances of effective therapeutic intervention and psychological and social adaptability. Beyond the visual impairment itself, LHON has significant consequences on quality of life. A holistic approach is essential—one that is centered on the patient's specific needs and focuses on managing the symptomatology in collaboration with the affected individual.

Methodology

The purpose of this research is to identify the social and professional challenges and difficulties experienced by individuals diagnosed with Leber Hereditary Optic Neuropathy (LHON).

Objectives

O1: Identification of the barriers and difficulties related to the socio-professional integration of individuals diagnosed with Leber Hereditary Optic Neuropathy (LHON).

O2: Exploration of strategies aimed at improving the socio-professional integration of individuals diagnosed with Leber Hereditary Optic Neuropathy (LHON).

Research questions

Q1: What are the barriers and difficulties in the socio-professional integration faced by individuals diagnosed with Leber Hereditary Optic Neuropathy (LHON)?

Q2: What are the strategies aimed at improving the socio-professional integration of individuals diagnosed with Leber Hereditary Optic Neuropathy (LHON)?

Sample and instrument

The research group consisted of 10 males from Romania diagnosed with Leber's hereditary optic neuropathy (LHON) in the last 10 years. They provided their own case studies, recounting their life stories from the onset of the first symptoms and all subsequent stages. There was no interview guide; instead, each respondent shared their case study during a 1-hour phone call, voluntarily.

Russell (2022) discusses the qualitative method based on the interview guide and life story. The life story represents a highly effective tool, especially in investigating the resilience of respondents. Both the researcher and the respondent co-create a narrative through the life story, which aids in identifying the resilience techniques used during the research process. González-Macías (2019) states that the life story as a qualitative tool is primarily used to highlight individual and personal experiences, offering an authentic perspective in the social field.

Data collection and processing

All respondents voluntarily participated in the research, and confidentiality and research ethics were fully respected. Relevant information for the research was extracted from the case studies, without any personal data. The case studies were collected via phone, starting from the life story related to the onset of the first symptoms. Each respondent presented their life story in approximately one hour. The respondents were aware of the purpose and objectives of the research.

Results and Discussion

Popovici and Diaconescu (2018) argue that individuals with visual impairments may face discrimination even within educational institutions, as these are often not adapted to meet their specific needs. The authors highlight several forms of pedagogical inadequacy, including the lack of curriculum modifications, insufficient teacher training to adequately respond to the needs of students with visual impairments, and unproductive attitudes. These attitudes may manifest either as lowered academic expectations—leading to social exclusion—or, conversely, as excessively high demands that contribute to the development of an inferiority complex. All these are forms of discrimination experienced by persons with disabilities.

Belibova (2018) considers that socio-professional integration depends both on the educational training of the young person with a disability and on the way society responds to this need. Often, individuals with visual impairments do not benefit from equal opportunities in accessing employment due to social segregation and prevailing prejudices.

Visual impairment affects individuals on multiple levels. In the educational sphere, institutions are expected to ensure equality among individuals, and to respect personal dignity and integrity. However, educational opportunities are often compromised due to various barriers, such as public negative attitudes and, most notably, inadequate equipment that fails to facilitate access to education for persons with visual impairments. Another significant barrier is the high cost of education, as institutions often struggle to procure specially designed educational materials for students with visual impairments. The lack of teacher training, inappropriate approaches toward individuals with disabilities, insufficient funding, and the rigidity of legislation are additional factors that hinder the educational process. (Omede, 2015)

The main themes that emerged from the data collection and analysis are: the onset of visual impairment and its impact on individual development, the importance of the family environment in personal development, forms of discrimination and social stigmatization of individuals with visual impairments, the interaction of persons with visual impairments with public and private institutions, the social climate and its role in the inclusion of individuals with visual impairments, psycho-emotional difficulties associated with visual impairment, and strategies for improving the quality of life of individuals with visual impairments.

Regarding the onset of visual impairment and its impact on individual development, the collected data indicate that the first visual problems appeared at the age of 20. The condition had a sudden onset, as the person began experiencing initial symptoms such as no longer being able to distinguish people around them, read, or follow university courses. The respondent initially thought they simply needed glasses or that the symptoms were caused by an irregular schedule and fatigue. They had been dealing with poor-quality sleep and a demanding work schedule for a long period of time. The respondent also mentioned facing financial difficulties, which delayed the decision to consult a specialist for a diagnosis. The first diagnosis received was incorrect, as the right eye was already severely affected, and the specialist assumed that the respondent had never had functional vision in that eye.

„Until 2017, at the age of 20, I had no health problems, and in May 2017 I began to notice the first signs—I started not seeing very well and thought it was due to a busy period. Then I realized I could no longer see well enough to write, read, or recognize people. At that moment, I believed it was just a matter of needing glasses, so I waited until I could afford a consultation. On June 1st, I finally went to an eye exam, and the woman there asked me if I had ever been able to see with my right eye."

After the first consultation and incorrect diagnosis, the respondent underwent frequent visits to both private ophthalmology clinics and public healthcare facilities in search of answers. The main issue was that each ophthalmologist provided a different diagnosis—ranging from optic nerve problems, neurological issues, multiple sclerosis, brain tumor, and optic neuritis, to the final diagnosis: Leber's hereditary optic neuropathy. The doctor who made the correct diagnosis informed the respondent that in the future, they would only be able to distinguish between light and darkness, as Leber's hereditary optic neuropathy is an incurable condition. The way the specialist communicated the diagnosis was direct and harsh.

„I was hospitalized for further investigations, and the initial diagnosis was optic neuritis. I then scheduled an appointment at a private clinic for July 10th, where I was given the correct diagnosis: Leber's hereditary optic neuropathy."

In terms of the influence of the family environment during the period of adjustment and understanding of visual impairment, data analysis reveals that the family provided support, particularly in how they responded to the new diagnosis. The paternal side of the family visited the Ministry of Health daily to present the case of their son and initiated a fundraising campaign due to the high cost of the medication, approximately 4,000 €. Financially, the family was highly involved; however, in the psycho-emotional sphere, they did not offer the moral and psychological support necessary for the patient to fully process and understand the impairment. The patient reported feeling, for a long time, like a "pet," as he was unable to perform any tasks independently and was treated by others as a helpless patient.

Following the diagnosis, genetic tests were conducted, revealing that the condition had been inherited from the maternal side. This was followed by a period of denial, frustration, and blaming the mother, grandmother, and maternal relatives, leading to negative and rejecting behavior. A bureaucratic issue arose concerning the initiation of the necessary procedures for disability classification and receiving the allowance. Upon encountering the term "disability grade," the respondent exhibited a sense of helplessness. Furthermore, the denial of the impairment resulted in a lack of recognition of the condition, which delayed the process of disability classification. Based on the provided information, the respondent's difficult relationship with their family is evident. The family was involved in all of the subject's decisions, even in choosing a psychologist to start therapy. However, the therapy was brief and did not help the respondent get closer to their family.

„I didn't feel well anymore, so I chose to stay in another city, even during the vacation when I didn't have university courses. I didn't want to stay with my family, I didn't accept their help, and I felt like they didn't know how to behave around me. I experienced a sense of rejection not only towards my mother but especially towards my grandmother; I behaved badly, thinking that she was actually the one to blame. The family environment wasn't one that could help me; I wasn't communicating with either the doctor or my family."

Following the diagnosis and the worsening of symptoms, the respondent began to experience situations of social exclusion. After the onset of initial symptoms and prior to receiving a definitive diagnosis, the respondent was hospitalized for a series of medical investigations. It was during the first days of hospitalization that he first experienced social exclusion: while resting and having left his phone beside the bed, he awoke to find it stolen—an act likely motivated by his visual impairment, which prevented him from distinguishing his surroundings.

In addition to this incident, the respondent noted a progressive breakdown in his social environment. Friends began to distance themselves as the illness progressed, and the respondent's perception of others became increasingly impaired. Another example of social exclusion occurred in the way his friends reacted upon learning of his diagnosis. Although physically present, they no longer greeted him; he could only hear their voices. The respondent reported that, apart from his dormitory roommates, no one communicated with him.

Further experiences of exclusion were reported during the 2017–2018 academic year, when the respondent was required to take his university exams. While most academic staff agreed to accommodate him by allowing oral examinations, one professor initially showed understanding but later applied pressure during the exam session, repeatedly questioning when the respondent would be able to see again and suggesting that it was inappropriate for him to be examined differently from his peers. Ultimately, the respondent received the lowest possible grade, which did not reflect his actual knowledge. Another discriminatory incident occurred during a team-based seminar assignment. One of his colleagues expressed disdain toward the respondent, criticizing him for his inability to see and contribute effectively to the group's work.

„ We were required to divide into teams for a group project, and one of my colleagues questioned why I had ended up in her team. She told me that I was of no help, that I was a burden, and that I was useless. She added that she should have chosen a classmate who could at least see, even if that person contributed nothing. Additionally, I had a professor who initially stated that the exam would be in multiple-choice format and that I would be accommodated—someone would read the items aloud to me. However, toward the end of the academic year, she began to exert pressure, repeatedly asking when my vision would return and asserting that I would not be able to pass the exam.People I used to spend time with would walk past me without greeting me or speaking to me. I would sit in front of the dormitory, unable to see, but I could hear them passing by."

Regarding the interaction that visually impaired individuals have with public and private institutions, the collected data indicate that the respondent lacks trust in the police authorities. After his phone was stolen, it took approximately one year for it to be recovered. In contrast to the disappointment experienced in this context, the respondent was positively surprised by the physician who confirmed his diagnosis. This doctor provided him with a voucher for free genetic testing and also connected him with a pharmaceutical company that could procure the required medication on the Romanian market.

The respondent expressed dissatisfaction with several physicians who offered him incomplete or inaccurate diagnoses, which did not reflect his actual condition. The Ministry of Health was another source of frustration, as frequent changes in leadership prevented continuity, and the medication he urgently needed was unavailable in Romania. This led to a profound sense of disappointment: for five months, the respondent lacked the necessary treatment, during which time his condition deteriorated significantly, ultimately resulting in complete vision loss.

In the educational sphere, some university professors excluded the respondent from student groups and failed to show empathy toward his diagnosis. However, the respondent continued his academic path and pursued master's studies after completing his undergraduate degree, thanks to the guidance and support of one faculty member who encouraged him to maintain social engagement. Another faculty member referred the respondent to an acupuncturist, which led to some improvement in his vision. Following several sessions, he was able to perceive writing on paper and distinguish people visually.

As a result of these experiences, the respondent underwent a significant shift in life perspective and decided to change his academic focus. For his master's program, he chose to study social work, driven by a desire to assist vulnerable groups.

„One university professor encouraged the respondent to pursue further studies in order to maintain social engagement and avoid isolation. Another faculty member recommended a physician specialized in acupuncture. After approximately one year of regular treatment sessions, the respondent reported a partial improvement in visual capacity. The medication required by the respondent was highly specific and unavailable due to the absence of a formal agreement (protocol) between the pharmaceutical company distributing the treatment and the Ministry of Health. Consequently, the respondent was deprived of necessary medication for a period of five months. During this time, his visual condition significantly deteriorated, leading to a complete loss of vision. The respondent described experiencing spatial disorientation in public spaces, including

accidental collisions with pedestrians due to the inability to distinguish environmental stimuli."

The respondent maintained stable social relationships only with his dormitory roommates at the university residence. These colleagues played a crucial role in supporting him through the challenges posed by his disability, which he perceived primarily as a handicap induced by the illness. The dormitory peers assisted him by reading course materials aloud, enabling him to retain information and complete his academic assessments successfully.

In contrast, the respondent reported a lack of support from other undergraduate colleagues, who tended to view him with pity and treated him as though he were fundamentally flawed. Their discomfort in being seen with him further reinforced his sense of social exclusion. Only a few close friends provided genuine emotional and psychological support, which contributed positively to his well-being.

Regarding romantic relationships, the respondent described an experience that brought both positive and negative effects. His partner offered a sense of emotional safety but also induced feelings of abandonment during periods of separation, especially when expressing romantic interest in others. This dynamic led the respondent to develop an insecure attachment style and emotional distress following the breakup.

In an effort to remain socially integrated and avoid feelings of marginalization, the respondent participated in cultural events and student conferences. However, rather than fostering inclusion, these experiences exacerbated his anxiety and frustration, primarily due to the persistent sense of stigmatization he encountered.

„The respondent stated that his dormitory roommates would read the study materials to him once, which was sufficient for him to retain the information and perform successfully in exams. His friends provided consistent psychological and emotional support, contributing significantly to his coping mechanisms and general well-being. The respondent also described entering a romantic relationship, which became a major source of emotional stability and confidence during that period. However, following the breakup—when his partner became involved with someone else—the respondent experienced significant emotional distress. He acknowledged developing a strong emotional attachment, and the abrupt end of the relationship, coupled with his partner's rapid shift of affection, left him struggling to accept the separation."

With the onset of visual impairments came psycho-emotional difficulties, both at an individual level and in interactions with public and private institutions. Consequently, adaptability led to the development of patterns and coping mechanisms aimed at overcoming vulnerabilities and defending against discriminatory situations.

In the early stages of the illness, the respondent avoided expressing emotions and personal experiences within their circle of friends and family, using laughter as a defense mechanism in response to the diagnosis, in an attempt to avoid appearing different or emotionally vulnerable. Another coping mechanism was based on physical appearance. The respondent began attending therapy sessions with a psychologist, but the situation eventually worsened, requiring consultation with a neuropsychiatrist and the initiation of medical treatment.

Dissatisfaction with the eye area led the respondent to grow and neglect facial hair in an attempt to divert first impressions—particularly from men—away from the eyes and toward the beard. From the onset of the illness through to diagnosis, the respondent experienced numerous panic attacks. This was followed by a difficult emotional period characterized by social withdrawal and refusal to contact family members.

Although the psychologist referred the respondent to a neuropsychiatrist, the referral was initially rejected due to a reluctance to take medication. The respondent attempted to recover independently, aiming to prove the psychologist wrong. However, the situation deteriorated due to sleep deprivation, recurring nightmares, and panic attacks, eventually leading to acceptance of medication.

The respondent also reported undergoing acupuncture sessions that resulted in significant pain. The emotional distress was further compounded by a lack of independence. Emotional well-being worsened when institutions failed to acknowledge the legitimacy of the partial visual impairment diagnosis and did not provide appropriate support. At the onset of the illness, the respondent refused to learn Braille, feeling that assistive technology would further emphasize their difference.

„I began attending sessions with a psychologist, who only asked me about my daily activities and not much else. I found myself sinking deeper and deeper emotionally. Eventually, the psychologist recommended that I see a psychiatrist and begin pharmacological treatment. I wanted to overcome the situation on my own and then return to that psychologist to prove that I had managed without medication. However, things deteriorated further—I experienced sleepless nights, recurring nightmares, and panic attacks during sleep."

Alongside the development of defense mechanisms, strategies for improving quality of life also began to emerge. However, the positive aspects were the most difficult to acknowledge. The respondent initially focused on gaining independence, striving to manage daily tasks alone for as long as possible in order to avoid feelings of helplessness and dependency.

One significant positive change was a shift in attitude toward the diagnosis. The respondent learned to extend greater compassion and empathy toward individuals with disabilities, expressing a desire to socialize and to understand the stories behind their impairments. Recognizing the self-imposed limitations became a strategy through which the respondent was able to appreciate personal successes and the overcoming of social barriers. Eventually, the disability came to be understood as something normal.

The respondent structured a supportive social circle made up of friends on whom they could always rely. They became aware of the pressure they had placed on themselves prior to the diagnosis, driven by dissatisfaction with their job, a desire to leave the country, and neglect of personal health. Although initially perceived as a burden, the disability was later understood as a turning point that helped slow down and recalibrate life.

At present, family relationships have improved, with communication becoming more effective among family members. The visual impairment has even become a catalyst for strengthening the bond with the respondent's father. Additionally, the disability fostered a deeper connection with spirituality, with the respondent acknowledging the importance of incorporating spiritual needs into their life.

„I became aware of the experiences faced by people with disabilities and developed greater empathy; I no longer avoid interactions with them. I was also able to recognize which friends remained by my side throughout the challenges. I sought to overcome the situation through spiritual means as well. Negative situations are often perceived as burdens, but they can also arise to ease our lives. Before the onset of my condition, I experienced high levels of stress, endured sleepless nights, and constantly thought about changing my job, leaving the country, and focusing solely on financial matters—neglecting my health in the process."

The illness has now reached a stable stage and is no longer progressing. In addition to the primary diagnosis, the respondent is also dealing with cardiac issues, which were identified following the onset of panic attacks.

Regarding the visual impairment, the respondent currently has no perception of distant objects, can distinguish people only when they are nearby, and is able to read large print but must be in very close proximity to do so. However, reading more than one page per day results in severe eye and head pain.

Professionally, the respondent aspires to work with children, to engage directly with individual cases, and to offer support—particularly in the field of disability. They express a strong desire to volunteer in various projects and activities, as well as a wish to relocate to another city in order to move beyond the negative experiences of the past.

Following this narrative, both the researcher and the individuals involved in the study may formulate specific arguments regarding strategies aimed at improving the quality of life for persons with disabilities. It becomes evident that the involvement of social workers and medical professionals is essential in the lives of individuals with disabilities. Healthcare specialists must also address the psycho-emotional dimension of the patient and intervene when psychological or behavioral changes are observed.

Social workers within disability assessment institutions should extend their role to include counseling services, while society as a whole must learn to distinguish between disability and impairment. Institutional collaboration requires restructuring, as each professional currently focuses solely on their specific domain, despite the fact that the patient represents a complex individual with multifaceted needs requiring integrated services.

Moreover, the inefficient management of time within hospital institutions constitutes a persistent issue that must be addressed through systemic reform and improved coordination among service providers.

„Society needs to learn the difference between the negative term 'handicap' and the phrase 'person with a disability.' The involvement of social workers or family doctors is crucial, as they should observe whether there is a need for psychological counseling. While each professional works within their own area of specialization, the issues faced by individuals are multifaceted, and it would be ideal to go to a hospital where all necessary investigations are done at once, rather than being sent from one specialist to another, with each providing a different treatment."

Specialized literature connects studies in the field with the results of current research. Guttman (2009) presents the term 'handicap' as an inability to exercise the capacity to participate in social life. In the current research, it is observed that the term 'person with a handicap' denotes helplessness and pity from others. Handicap becomes evident when the person in question faces social inaccessibility.

Turchina and Popov (2011) discuss the concept of visual impairment, which refers to both partial and total loss of vision. In the present study, participants consider it important for society to understand that a person with a visual impairment does not have to have total vision loss; partial impairment can also exist.

The similarities between Mustață's (2019) work and the current research are significant. Both show a connection between the onset of a condition and the presentation of depressive symptoms in patients. Another similarity is related to the manifestation of heart problems that arise alongside the presence of anxiety and depression in the person's life.

Phillips and Proulx (2018) highlight the importance of observing non-verbal language in a person's life, as its absence can convey frustrations and anxieties, leading to social isolation, which the results of the current study confirm. Visual impairment exists, but hearing functioned, and individuals recognized others by the tone of their voice, yet there was disappointment as they were not included in the previous friend group due to their disability.

Swain et al., (2003) emphasize the importance of organizational involvement in improving the quality of life for people with disabilities. As indicated by the current research, there is a desire to improve the medical and social system through institutional collaboration

Conclusions

The first research question is associated with the barriers and difficulties in the socio-professional integration experienced by individuals diagnosed with Leber Hereditary Optic Neuropathy (LHON). The research findings indicate that upon receiving the diagnosis, the family environment faced communication challenges, particularly on the maternal side, as the disease is maternally inherited. Consequently, familial integration was altered, with individuals expressing blame toward their maternal relatives for their suffering. Social relationships became strained and shadowed. Discrimination and social stigmatization were reported from the onset of symptoms, with participants facing painful remarks from university peers and professors, and experiencing pity and humiliation. Close acquaintances withdrew from social interactions due to the shame of being seen in public with a visually impaired person. From the social to the educational environment, the pressure of visual impairment was strongly felt.

Interactions with both public and private institutions were described as disappointing, particularly due to one respondent’s inability to access necessary treatment for five months, a delay caused by the lack of a signed protocol between the Ministry of Health and the pharmaceutical company responsible for supplying the medication in Romania. As a result, their vision deteriorated further.

Social relationships fluctuated between periods of difficulty and moments of support. On a psycho-emotional level, participants reported episodes of depression and anxiety, having developed defense mechanisms in response to a society marked by social exclusion. Emotional difficulties included panic attacks, which led some individuals from therapy sessions to consultations with neuropsychiatrists and the need for medication.

The second research question focuses on strategies aimed at improving the socio-professional integration of individuals diagnosed with Leber's Hereditary Optic Neuropathy (LHON).

The findings reveal that, alongside the diagnosis and resulting visual impairment, participants reported several positive transformations. These included a shift in attitudes toward individuals with disabilities, increased involvement in volunteer programs and disability advocacy, and the development of compassion and empathy toward others facing hardship—motivated by the desire to understand the personal stories behind disabilities.

The disability was often perceived as a spiritual and positive turning point. Participants also reported improvements in their social relationships. For some, the onset of the disability marked a period of personal reflection and relief from the material and financial pressures of daily life.

Over time, the initial challenges were gradually overcome, and participants began to focus on future opportunities. These include socio-professional advancement, continued volunteer engagement, and pursuing careers aligned with supporting vulnerable populations.

Furthermore, in the future, it is essential for social workers and medical professionals to work collaboratively in identifying and addressing both the medical and emotional needs of individuals diagnosed with LHON.

The role of the social worker within the disability assessment services must also extend beyond administrative evaluation to include counseling and emotional support. Moreover, society should learn to distinguish between the legal notion of disability and the actual lived experiences and challenges faced by individuals with disabilities.

Institutional collaboration requires restructuring, as professionals often operate within isolated domains. Yet, the individual—viewed holistically—requires an integrated, interdisciplinary approach that combines medical, psychological, and social services.

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