THE PERCEPTION OF BLINDNESS AND ITS IMPACT IN THE IMPLEMENTATION OF EMOTIONAL SUPPORT FOR SIGHT LOSS IN MEXICO: A PSYCHO-SOCIAL STUDY IN REHABILITATION CENTRES

LESLIE THOMPSON

A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Doctor of Philosophy in Psychosocial Studies

Faculty of Health and Applied Sciences, University of the West of England, Bristol

November 2023

Abstract

This research is the first psycho-social study to explore the perception of blindness and its impact on the implementation of emotional support for people with sight loss in rehabilitation centres in Mexico.

At an individual level the study deepens the understanding of sight loss as a process involving loss, mourning and reconstruction of identity, extending Thurston's Five Stage Model (2010). At a social level, other key aspects of the research include how perceptions of blindness in Mexico are shaped by cultural constructs such as the Charity Model of Disability introduced in the Spanish colonial period. This model fosters ableism and a social hierarchy that devalues people with impairments, while placing people without impairments as their saviours. These historical influences are mirrored in the contemporary healthcare and educational landscape, marked by resource disparity that perpetuates disability and intersects with class oppression.

Identifying individual psychological adjustment needs of people with sight loss to the care providing organisations was a positive outcome of the work. The researcher developed and implemented a specialist training protocol for psychologists and staff working at the rehabilitation centres, embodying an academic activist approach.

The findings suggest that a positive environment, social support, and inclusion opportunities are crucial for the adjustment to blindness. However, they also shed light on the problems of inaccessibility of education and scarce work opportunities, mainly linked to manual low wage occupations.

Finally, the interlinked nature and interplay of individual, social and cultural levels for people with blindness in Mexico is given a theoretical elaboration by adapting Lacan's Borromean knot concept, addressing the real (physical loss), the imaginary (personal and social meanings of sight loss) and the symbolic (cultural norms) dimensions, and calls for collective action from clinicians, academics, and activists to dismantle these systemic barriers and foster a greater social inclusivity.

Key words: Emotional impact of sight loss, Five Stage Model, Psycho-social studies, perception of blindness in Mexico, Charity Model of Disability, implementing emotional support for people with sight loss at rehabilitation centres, training protocol for psychologists and staff of rehabilitation centres for sight loss, academic activism, Borromean knot.

Word count: 81,858

Do not go gentle into that good night

Rage, rage against the dying of the light

Dylan Thomas (1952)

Contents

1.- Introduction

This research is the culmination of my 25-year journey to implement emotional support for people with sight loss in Mexico.

Twenty-five years ago, my mother lost her sight. I was five years old and became her principal carer. At the time, rehabilitation services and emotional support were unavailable in Mexico, our country of residence. The emotional impact of sight loss on my mother was something she never recovered from.

Additionally, we were surrounded by social conditions that placed my mother in a position of uselessness. My father left, saying the situation was too much for him. My family (my mother's siblings) helped her from a charity perspective; they would pay for the bills but exclude us from family plans because we were too much to handle, a burden. Most of my mother's friends slowly stopped visiting her. She was never able to find a job, partly because of the lack of inclusion for people with impairments but primarily because of my family's perception of uselessness, which became her own.

My mother felt frustrated, angry and depressed every day for nine years. Some days she cried for hours; others, she screamed from desperation and on the worst days, she hurt herself. My experience through those years was filled with pain, both hers and mine, that I didn't know how to handle. Section 1.1.1 deepens my experience with my mother as my early life influences that led to this study.

The term *wounded healer* suggests that healing can emerge from a healer's woundedness. What is relevant is not the degree of woundedness but the ability to draw on that woundedness for the purpose of healing (Zerubavel & O'Dougherty, 2012). After her death, I set my mind to understanding the grieving process of sight loss and doing something so that people going through this process can have access to a space to elaborate this loss. I wanted to provide an alternative to the emotional strain my mother and I went through. I needed to transform my experience. Otherwise, it would have been just pain.

Then, my journey began.

I decided to study Psychology to understand the emotional impact of sight loss. After conducting two studies exploring the emotional impact of sight loss from a psychodynamic perspective (section 1.1.2), I proposed including emotional support for people with sight loss at the centre that didn't have rehabilitation services when my mother lost her sight. They replied that emotional support wasn't relevant for a person to adjust to sight loss. I knew emotional support was an important tool to offer to people with sight loss, but I couldn't understand why the rehabilitation centre was saying it wasn't.

Therefore, this research represents my shift from a psychological background in which I wanted to understand the internal, psychological process of sight loss towards the incorporation of the social context and the role that society plays in this process. To do this, I decided to use a psycho-social methodology because, as a discipline, psycho-social studies explore the intersection between the individual and society, following the premise that one is not admissible without the other (APS, 2023).

From a psycho-social perspective, the aims of the study were to:

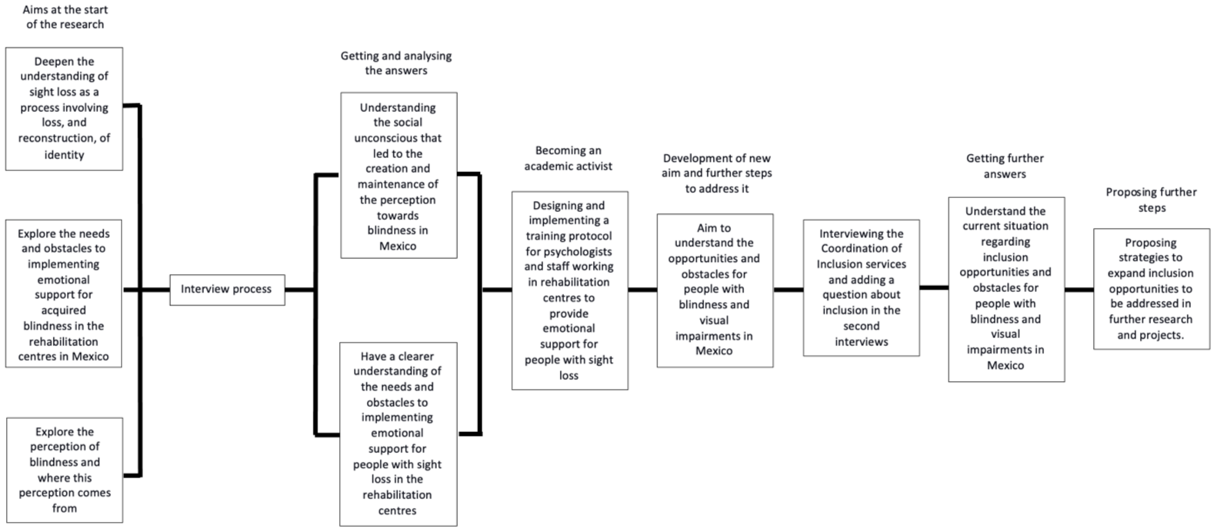
1. Deepen the understanding of sight loss as a process involving loss, and reconstruction, of identity,
2. Explore the needs and obstacles to implementing emotional support for acquired blindness in the rehabilitation centres in Mexico, and
3. Explore the perception of blindness and where this perception comes from.

Nonetheless, the research journey led me to expand the aims of the study. Once I had understood the social unconscious that led to the creation and maintenance of the perception towards blindness in Mexico, I had a clearer understanding of the needs and obstacles to implementing emotional support for people with sight loss in the rehabilitation centres. This led me to design a training protocol for psychologists and staff working at the centres. Through this research, I became an academic activist and had the opportunity of implementing this protocol and train psychologists and staff members in how to provide emotional support for people with sight loss (section 4.4).

As I was addressing the gap to provide emotional support for people with sight loss, I started wondering about inclusion. Once a person with sight loss has gone through a grieving process and has gained tools to continue performing everyday activities, where are they going to adjust if Mexico is not adapted for people with blindness and visual impairments?

Thus, this research took a further step in exploring inclusion opportunities and obstacles for people with blindness and visual impairments to shed light over the current situation in Mexico and propose ways to address it.

The following diagram shows the progression of the research aims through this study:



After presenting the early life influences that prompted this journey (section 1.1) and the research projects that precede this study (section 1.2), section 1.3 sets the context in which this research takes place. Section 1.3.1 expands on a global vision of blindness, including definitions, worldwide statistics, and the programmes currently developed to address preventable blindness by the World Health Organization. Then, section 1.3.2, narrows on the geographical frame of the study, presenting the current situation within Latin America and Mexico, including the prevalence of visual impairments and the prevention, treatment and rehabilitation strategies being currently implemented. This section aims to shed light over the current opportunities and obstacles faced by people with blindness and visual impairments in this country.

Chapter 2 presents a review of the literature, both from a psychological and a sociological perspective, that guided this project. Chapter 3 presents the psycho-social methodological approach for gathering and analysing data for this research. Chapter 4 presents the findings of this study. Chapter 5 discusses the data gathered from the study (chapter 4) and its meaning in relation to both the reviewed literature (chapter 2) and my journey through the research (chapter 3). Chapter 6 presents the conclusions and account of this research journey.

Finally, chapter 7 presents final reflections on the personal meaning of this study. As mentioned before, this research is the conclusion of my 25-year journey to implement emotional support for people with sight loss in Mexico. Through this study, I was not only able to explore and understand the role society plays in relation to the lack of access to emotional support for people with sight loss at the rehabilitation centres for blindness in Mexico, but I was also able to develop and implement this service.

As I was conducting this research, I had the opportunity to connect with the Royal National Institute of Blind People, train as a counsellor for sight loss, and adjust their emotional support protocol to the Mexican population. Now, I train psychologists working with people with sight loss and implement this service at rehabilitation centres for blindness.

Additionally, and because of my shift of perspective to a psycho-social position through this research, I have also started developing inclusion projects to create awareness in society so that people with blindness and visual impairments are included in every aspect.

After 25 years, I have given meaning to that painful experience. People with sight loss in Mexico can access emotional support during their rehabilitation process, and we're slowly changing the social perception towards people with blindness and visual impairments. They now have an alternative my mother and I didn't have.

This research is the journey that led to that achievement.

1.1 Early influences in this study

My mother lost her sight due to diabetic retinopathy when she was 33 years old. I was five. My parents separated three months after her sight loss. As an only child, I became the principal carer of my mother.

My mother and I lived alone at my grandparent's house (both had passed). My mother's siblings helped us financially, and I took care of her needs, including her medical care (insulin, medicine, dialysis, etc.) and her everyday care, such as bathing, dressing, and feeding her.

My mother lost her mobility and became completely dependent on those around her. Reflecting on this, I do not understand why she became physically impaired when she didn't have a physical condition that stopped her from walking or performing everyday activities. I believe this is related to the social perception projected into my mother. My aunts and uncles treated her as if she could not do anything, and they excluded us from gatherings because "we were a burden." My mother accepted this position of inability and burden. She never tried to find resources that could help her walk again, learn to use a cane, or develop tools to be independent in her everyday life. At the time (1998), the social stigma towards people with impairments was worse than today, so finding a job would have been challenging, if not impossible, for her. Nonetheless, she didn't even try. She adopted a position of uselessness. Whenever she knew my family got together without inviting us, she would cry and say she hated herself for being a burden.

My family is devotedly Catholic. My mother and her siblings prayed for a miracle that would return her sight to her. Additionally, they used Catholicism to try to find a meaning for her blindness. As an explanation, they said she was living a purgatory on Earth. With her suffering, she was saving both her soul and other souls that were stuck in purgatory and couldn't get to heaven. My mother needed to suffer, they interpreted, to save them. Through her purgatory on Earth, it was guaranteed that when she died, she would go to heaven. Additionally, they said I was an angel sent by god with the sole purpose of caring for my mother. I believe this explanation served as an attempt to give my mother a reason to hold on through her suffering, but also as a justification for their treatment towards us.

Losing sight caused deep suffering in my mother. When she struggled to do something or find something, she would cry and yell to herself that she was stupid, useless and a burden. Despite my attempts to help her and hold her pain, it was overwhelming for both of us.

Four years after she lost her sight, a friend of my mother told her she knew someone that worked at a charity for people with blindness. This charity provided free medical treatment for visual conditions and was starting to design a rehabilitation area. Through my mother's friend, this charity gave us material to learn braille. Learning braille together helped our relationship as I could now write notes or letters to her, but at the time there were no books for her to read in braille that we could access. Additionally, the centre didn't yet offer any rehabilitation courses or provided emotional support. Furthermore, back then, just as it is now, emotional support carries a social stigma of being for "crazy or weak people."

My mother died nine years later from an infection caused by complications from kidney failure. She had never adjusted, either practically or emotionally, to sight loss. She died wanting to see again.

After my experience with my mother and having lived as a proxy the deep emotional suffering that comes with sight loss not only for the person living it but for their family and loved ones, I made my life's purpose in contributing to creating an alternative for people with sight loss to not go through what my mother did, and for no family member to go through what I did.

1.2 Building the path

Since I started my professional career, I've been researching to understand the physical, emotional and social dimensions of sight loss to bridge the gap in access to emotional support in the rehabilitation centres for blindness in Mexico.

To understand the emotional dimension of sight loss, I studied for a bachelor's degree in Psychology. My first idea for my thesis was to research the stages of the grieving process of sight loss. When I was reviewing the literature, I found that there were already four models that explained the grieving process of sight loss (Allen, 1989; Hayeems et al., 2005; Thurston, Thurston & Mcleod, 2010; Tuttle & Tuttle,1996). These models are explored further in 2.3.2. As my initial question was already answered and a sight loss model already existed, I changed my research project to explore the factors that aided or hindered the adjustment process of sight loss for adults. My teammates and I conducted this research at the charity that had previously given my mother and me tools to learn braille. At the time (2013), they had already built a rehabilitation programme that included early stimulation for children with visual impairments, braille, orientation and mobility, everyday life activities and computers.

To gather the data, we interviewed adults with sight loss that had lost sight as adults using the Life-History method. The results of the study were consistent with the literature. Factors such as optimism, determination, desire to adjust to sight loss, productivity, perseverance, independence and the presence of a support network were considered helpful in the adjustment process to sight loss. In contrast, lack of purpose, difficulty in accepting sight loss, negative self-evaluation, dependence and feelings of vulnerability were found to hinder the process (Thompson et al., 2013).

What caught my attention was that the charity administrator told us that the participants were already adapted to blindness, and interviewing them about their grieving processes was a waste of time. Nonetheless, the participants talked about their difficulty in coping with blindness. They mentioned feeling depressed, scared and anxious. A participant reported consuming cocaine to avoid thinking about his sight loss. Another one mentioned having a loaded gun under his bed "for the day when he can no longer endure the pain of not being able to see" (Thompson et al., 2013, p. 80). The emotional impact of sight loss on the participants was alarming and demanded immediate attention. Nonetheless, the complete opposition of ideas between the staff's perception and the participants' experience was shocking. I couldn't understand why the centre ignored the participants' emotional experiences.

When we finished the research and based on the results, we recommended the charity to incorporate emotional support as part of its rehabilitation plan. They replied that emotional support wasn't needed for someone to adjust to sight loss. I knew from my experience with my mother that sight loss is a profound loss that requires physical adjustment and emotional support. Nonetheless, besides the research findings, I didn't have the tools at the time to explain the depth of this loss and why offering access to emotional support was crucial.

To deepen my understanding of the emotional implications of sight loss, I decided to pursue a master's degree in Clinical Psychology with an Advanced Track in Psychoanalysis. I wanted to learn how to explore the unconscious to understand why a person, or a society, is the way it is. I trained as a psychoanalytic psychotherapist and wrote a theoretical thesis on understanding sight loss as a loss and reconstruction of identity from a psychoanalytical perspective (Thompson, 2017). This work is presented in section 2.3.2.

Freud's theorisation of grieving and mourning defines a *grieving process* as knowing what is lost but not what's lost in it (Freud, 1914). Blindness is commonly minimised to the physical dimension of losing an organ's function. Nonetheless, it has psychological and social dimensions that are constantly overlooked. My master's thesis explored the psychological dimension, concluding that sight loss represents losing not only the possibility to keep performing in a world made by and for sighted people but also one's own identity as a sighted person. Additionally, it represents the lack of capacity to recognise and be recognised by others visually, and thus the need to find new ways to reconstruct one's identity and provide a gaze to others through other senses. This research also theorises that the rejection from sighted people towards people with blindness could be related to the fact that people with blindness cannot provide a visual reflection in which sighted people could mirror to reconstruct their identity (Thompson, 2017).

Therefore, to adjust to sight loss, one must accept blindness and renounce the possibility of seeing to be able to reconstruct a new identity as a person with blindness and make use of the other senses (Lampl & Olivier, 1985). This was further elaborated by Thurston, Thurston & Mcleod (2010), who developed the Five Stage Sight Loss

Model, a theoretical model that proposes that for sight loss to be elaborated, a reconceptualisation of the self as a person with blindness must take place. Furthermore, Thurston proposes that emotional support will be needed at different moments of the process depending on each person's needs. This model is further elaborated in section 2.2.

After acquiring a master's degree in clinical psychology, I started working as the Coordinator of the Graduate Programmes in Clinical Psychology at my university. I went back to the charity in which I had done my bachelor's thesis and offered to provide emotional support to people undergoing a rehabilitation centre without cost by masters students from the university who were training for their clinical degree. The centre's administration responded again that people with sight loss didn't need emotional support to adjust to blindness. I felt devastated.

Having had a personal experience and after conducting an in-depth literature review and two research projects that prove the relevance of emotional support to adjust to sight loss, I immediately set my mind to answer the following question: Why was the centre saying emotional support wasn't relevant for someone to adjust to sight loss? Why was this the perception of the rehabilitation centre? What was the centre *seeing*, and why couldn't they *see* the emotional experience of the people going through a grieving process for sight loss?

I started researching for PhD programmes that could help me address these questions. Through the Association for the Psychoanalysis of Culture and Society, I started learning about Psycho-social studies and the intersection it provided to research a sociological problem from a psychoanalytical perspective using a qualitative methodology drawn from the psychoanalytic technique. It was perfect for what I wanted to address, and I applied to the PhD programme in Psycho-social studies at UWE. My doctoral thesis project aimed to answer those questions by exploring the perception of blindness and emotional support to understand the needs and obstacles to implementing emotional support in rehabilitation centres for blindness in Mexico. This was the first study conducted in Mexico that explored blindness from a psycho-social perspective. It was the first step towards generating awareness and to start including emotional support for people with sight loss at rehabilitation centres for blindness.

1.3 Setting the context

This chapter aims to set the context in which this research was developed. Section 1.3.1 presents a global vision of blindness, including statistics of blindness and visual impairments, as well as the initiatives being developed worldwide to avoid preventable blindness. Section 1.3.2 delineates the study's geographical frame. This section provides information on efforts to avoid preventable blindness, treatment for visual conditions, and rehabilitation programs in Latin America and Mexico.

1.3.1 World Vision of Blindness

According to the World Health Organization (2023), at least 2.2 billion people have a visual impairment. From those 2.2 billion cases, at least 1 billion could have been prevented. Globally, the leading causes of visual impairment are age-related macular degeneration, cataracts, diabetic retinopathy, glaucoma and uncorrected refractive errors. Nonetheless, there is a significant difference between countries in the manifestations of these impairments due to factors such as the availability of eye care services, their affordability and the education people have about visual health. For example, the prevalence of cataracts is higher in low- and middle-income countries, where access to simple procedures is limited. On the contrary, glaucoma and age-related macular degeneration are more prevalent in high-income countries. In children, the leading cause of visual impairments in low-income counties is congenital cataracts, while in middle- and high-income counties is retinopathy of prematurity (WHO, 2023).

The primary risk factor for visual impairment is ageing, which can cause presbyopia, cataract, glaucoma, and age-related macular degeneration. Genetics is the second leading factor, causing impairments such as glaucoma, refractive errors and retinal degeneration. Lifestyles, such as smoking (which can cause early onset of cataracts and macular degeneration), malnutrition (vitamin A deficiency cause corneal opacity), and activities such as contact sports (risk of ocular injury) are also significant factors for visual impairment. Environmental risk factors, such as hygiene, sanitation and access to clean water influence the transmission of infections that can cause blindness. Health conditions such as diabetes, rheumatoid arthritis, multiple sclerosis and pre-term birth can also develop sight loss. Many eye conditions are multifactorial (WHO, 2019).

Several social barriers prevent access to visual health services. In some countries, particularly low- and middle-income countries, women do not have access to health services. On the other hand, in high-income countries, men are less likely to seek eye care. Worldwide, a low socioeconomic status has been reported as a factor that limits access to eye care services. Limited access to education also plays a crucial role in access to eye care services as it represents a lack of knowledge of visual conditions and eye health services. This lack of education and health accessibility poses a risk for the vulnerable population. Additionally, people with other disabilities (hearing, physical or intellectual) have more challenges in accessing visual health services because most health institutions are not adapted for other (or multiple) impairments, there is a lack of resources, or health care providers are not trained to treat various impairments (WHO, 2019).

Efforts of the World Health Organization aim to establish visual health protocols to avoid blindness. Their World Report on Vision (2019) begins with the following foreword:

> “In a world built on the ability to see, vision, the most dominant of our senses, is vital at every turn of our lives. The newborn depends on vision to recognise and bond with its mother; the toddler to master balance and learn to walk; the schoolboy to walk to school, read and learn; the young woman to participate in the workforce; and the older woman to maintain her independence. However, as this report shows, eye conditions and vision impairment are widespread, and far too often they still go untreated” (World Report on Vision, 2019, p. V).

The global initiative “Vision 2020: The Right to Sight” was crucial to accelerate the development of national eye care programmes to prevent blindness. Substantial progress has been made, such as the worldwide decrease of people needing surgery for trachoma from 8.2 million in 2007 to 2.5 million in 2019 and the increase in rates of cataract surgeries in low- and middle-income countries (WHO, 2019).

In the World Health Assembly of 2019, the challenges facing health services in the eye care factor were recognised as eye care services being inequitable distributed, of unequal quality and poorly integrated across health programmes and sectors, and these services provided by an uncoordinated and sometimes unregulated workforce. Additionally, there is a lack of integration of eye care-related information (WHO, 2019).

For the first time since the WHO addresses eye care in their meetings, the impact of visual impairments and blindness and the quality of life was outlined as follows:

- In children, visual impairments can impact delayed motor, language, emotional, social, and cognitive development that can bring lifelong consequences. They can also experience difficulties in educational achievement and lower self-esteem in relation to their sighted peers.

- Adults with visual impairments tend to have lower rates of workforce participation and productivity and higher rates of anxiety and depression.
- In older adults, visual impairments enhance social isolation and dependency, as well as limited mobility and cognitive decline.

Visual impairments also have an impact on family members and carers, who provide assistance for daily living, such as taking children to school, shopping, cooking, cleaning, etc. Although social support has a positive influence on people with visual impairment and aid in adjustment to life without sight, providing this support can have physical and mental consequences for carers, particularly when the carer has to take on significant aspects of the life of the person with a visual disability due to a lack of a social response that facilitates inclusion for people with visual impairments (WHO, 2019).

Blindness also has a significant impact on society. The Global Burden of Disease Study (2017) mentioned that blindness and visual impairments are the third cause of societal burden due to their impact on employment. Consequently, this poses a financial burden due to productivity loss. For instance, the annual cost of moderate to severe vision impairment ranged from .01 billion USD in Honduras to 16.5 billion USD in the US (WHO, 2019).

The investment needed to prevent vision impairments is estimated at 32.1 billion USD. In low- and middle-income counties, 23 million health workers would need to be hired and 415,000 health facilities built. A shortage of trained human resources is one of the most significant factors that lead to the incapacity to prevent visual impairments (WHO, 2019).

The next step of the Visual Health agenda to address these challenges is to include eye care in the Universal Health Coverage by the United Nations. This would include providing eye care services according to the population’s needs, ensuring financial possibility to address health coverage and moving towards an Integrated People-Centered Eye Care (IPEC).

IPEC provides a range of health interventions that address people's needs regarding visual health throughout their life. The implementation of IPEC requires four conditions (WHO, 2019):

- Empowering and engaging people: every country must develop a targeted policy and interventions to create awareness of visual health.
- Reorienting the health care model: designing innovative and effective healthcare services that prioritise primary and community eye care (through primary medical care at school and other communities).
- Coordination between health service sectors: promotion of team-based care and referral systems.
- Creating an enabling environment: providing frameworks for the engagement of the state and private actors in eye care sectors, developing a health information and surveillance system for producing information and optimising the supply of visual healthcare professionals through revising education and labour market.

The World Health Organization has gathered worldwide information, presented a report on the current issues regarding access to visual health care and proposed a framework that aims to include eye care in the primary health plan. This work is crucial for the prevention of avoidable blindness.

Nonetheless, if blindness cannot be prevented, the WHO's guideline is to create awareness of visual rehabilitation services in the community. In places where rehabilitation is not available, people should advocate for them (WHO, 2019).

Rehabilitation services aim to optimise functionality in people with blindness or visual impairments by providing practical adaptations to address the social, psychological, emotional, and economic consequences of visual impairments. In relation to the detailed 180-page report on the current visual health care situation and framework for strategies to prevent blindness, on the one page that addresses rehabilitation, there are no clear guidelines on how to develop these programmes or strategies. The emphasis is clearly on primary and secondary health care (prevention and treatment), which is very important. Nonetheless, (at least in this report) people whose visual impairment cannot be prevented or treated are not included in strategies to ensure their integration into society (WHO, 2019),

The WHO aims to eliminate blindness and visual impairments, consequently leading to not having to design rehabilitation and inclusion strategies. Nonetheless, this initiative is not yet 100% successful as there are still sectors with limited access to visual care as well as eye conditions for which treatment have not yet been developed. Therefore, there are still people living with blindness and visual impairments who are not being considered by WHO's initiatives or that are not considered with the same priority. People with unavoidable blindness are (or should be) as important and valuable as those whose visual impairment can be prevented. Thus, rehabilitation strategies should be as promoted as the prevention and treatment of visual impairments. Additionally, the emotional impact of sight loss is mentioned once in the report. Although it is being recognised, there is no further elaboration on this impact or treatment guidelines.

The task of promoting rehabilitation and inclusion strategies is taken on by the World Blind Union (WBU). WBU is an organisation created by people with blindness that represents people with blindness and partial vision at the United Nations. The objective of the WBU is to make the world a better place for people with blindness and visual impairments. Through working committees, such as the UN advocacy network, human rights committee, employment committee, or committees that support specific populations (women, young and older people), the WBU supports their advocates to promote strategies and frameworks in different countries to create changes for the inclusion of people with blindness and visual impairments (World Blind Union, 2023). Interestingly, counselling accessibility or guidelines for people with sight loss are also not mentioned by the World Blind Union. It seems like emotional support for people with sight loss is lost in the transition from medical attention to inclusion, somewhere in the un-mentioned rehabilitation services.

WHO has a strong global voice. The fact that their World Report on Vision (2019) does not include guidelines for rehabilitation but focuses solely on the prevention and treatment of blindness and visual impairments sends the underlying message that people whose visual impairment is nonavoidable are “less important” (1 page out of 180 less important). Their guidelines, secondarily, push countries to set their efforts toward designing national strategies to avoid and treat preventable blindness, which is excellent. However, it is not accompanied by efforts for rehabilitation and inclusion of the millions of people whose blindness and visual impairments are not preventable. At this point, until (and if) blindness is eradicated, both efforts are equally important.

The WHO (2019) provides a framework as to what each country must consider for the United Nations to include visual health in its inclusion of people with disabilities. Nonetheless, they leave the options open for each country to develop their own strategies. Therefore, to develop any programme (prevention, treatment or rehabilitation), it is first crucial to understand the social aspects surrounding visual impairments in the country of interest.

Therefore, the next section sets the frame of Latin America and Mexico, where this research was developed. It provides information on the current prevalence of visual impairments and strategies for prevention, treatment and rehabilitation.

1.3.2 Geographical frame of the study: the current situation

The Pan American Health Organization (PAHO) is the WHO regional committee for the Americas. This committee is dedicated to endorsing the strategic lines of the World Health Organization in Latin America. PAHO supports governments in developing guidelines for the prevention of blindness through education and awareness of visual health care and strategic treatment. In Latin America, evidence shows that blindness and severe visual impairments are predominant in rural and low-income sectors. Thus, PAHO provides technical support in planning, strengthening, monitoring and evaluating public visual health in those sectors to reduce inequalities in service provision (PAHO, 2023).

The International Agency for the Prevention of Blindness (IAPB) divides Latin America into four regions according to their geographic zone: Central, Andean, Tropical and Southern. In Central America (where Mexico is located), the prevalence of sight loss is 12.8%, which means 33,864,373 people with blindness or visual impairments (IAPB, 2023).

50% of blindness in Latin America is caused by cataracts, the leading cause of blindness in LATAM. Therefore, 50% of blindness in these countries could be treated with simple surgery. The lack of treatment for a curable condition provides evidence of the lack of education, resources, and personnel in Latin American counties. 41% of childhood blindness is registered due to Retinopathy of the Premature, and one in ten people with diabetes develops diabetic retinopathy, a consequence of another condition that, in most cases, can be prevented (IAPB, 2023).

The *Unión Latinoamericana de Ciegos* (Latin American Union of the Blind-ULAC) represent people with blindness and visual impairments in Latin America and the Caribbean at the World Health Organization, the World Blind Union, and the Organization of American States. The ULAC acts to promote and defend basic human rights and liberties for people with blindness and visual impairments in Latin America, promoting their social participation and political incidence (ULAC, 2023).

In 2010, the ULAC developed a Technical Manual for Integral Rehabilitation Services for People with Blindness or Visual Impairments in Latin America. In this manual, they provide a clear guideline for implementing rehabilitation models, including rehabilitation modalities, professional requirements of personnel, functional rehabilitation, visual rehabilitation, and professional rehabilitation. (ULAC, 2010).

In this document, *psychological treatment* is included as one of the bare minimums required in a rehabilitation model, along with medical attention, orientation and mobility, daily activities, braille, computers, mathematics, and the development of manual skills (UCLA, 2010).

This document mentions that blindness and low vision influence personality. Additionally, a visual impairment impacts the possibility of living an independent life and affects the family and social environment. Losing sight, the main communication channel, leads to isolation, inactivity, insecurity, loss of confidence and dependence. It represents a trauma that has an emotional impact that affects personality, as well as the possibility to keep belonging to society. These effects lead to creating efforts for the rehabilitation process to not only focus on the physical loss or alteration but also to consider the emotional impact, frustrations, and social limitations (ULAC, 2010).

According to this document, psychological support must be provided throughout the program, and not only to the person with sight loss but also to their family. They define anxiety, depression and low self-esteem as factors that will be present invariably in a person with sight loss. Additionally, cognitive factors such as ideas and attitudes towards blindness can vary from one person to another. As blindness or severe visual impairments affect people differently, the psychological work must be personalized, considering individual differences, personal profile, family history, social and working circumstances, degree and way of sight loss and the perception towards blindness and visual impairment (ULAC, 2010).

The goal of the psychotherapy program for the individual is to promote the acceptance of blindness and offer emotional and cognitive tools that facilitate social insertion. For the family, the objective is to unify rehabilitation expectancies, avoiding attitudes and behaviours of overprotection or rejection. At an academic and work level, the goal is to facilitate adjustment or readjustment considering the individual challenges. At an institutional level, the psychologist's task is to promote spaces to elaborate alternatives to the challenges faced in the rehabilitation processes by the staff and educate about the psychological impact of blindness. Also, the psychologist is responsible for creating community awareness about visual impairment and promoting social inclusion initiatives. This manual proposes specific guidelines for how to perform each of these tasks. "The psychologist is the oil of the motor" (ULAC, 2010, p.24).

Professionals from Colombia, Uruguay, Chile, and Cuba elaborated this manual. Mexico did not participate in the committee that developed these guidelines, nor has it adopted these strategies. With this in mind, we move forward to introducing the context of Mexico regarding statistics of blindness and visual impairments as well as prevention, treatment and rehabilitation programmes.

México

In Mexico, there are approximately 2 million 237 thousand people living with a visual impairment, from which 415, 800 people have blindness. Mexico is located within the 20 countries with the highest number of people with blindness and visual impairments (Cámara d Diputados, 2020).

Between 40 and 50% of the cases of people with blindness are due to cataracts, followed by diabetic retinopathy (20-30%), glaucoma (15-25%), retinal detachment

(6%), degenerative myopia (5%), cognitive malformations (4%) and other causes. The leading cause of blindness in Mexico is cataracts, a condition that is reversible with surgery (Gobierno de Puebla, 2020).

Access to health care in Mexico is limited. The Instituto Mexicano del Seguro Social provides free health care to all people listed as contributors, but the quality is deplorable. Besides public health care, some private hospitals offer healthcare care at an expensive cost. For those who are not contributors and cannot afford a private hospital's price, there are associations throughout the country that are either funded by the government or privately sponsored. There is no national platform where all the associations are registered. Government-funded associations are registered on official web pages, while privately sponsored associations are advertised by their partnerships and sponsors. There are no communications or a registration system between the organizations.

The member organization representing Mexico in the World Blind Union is the Asociación Mexicana para la Atención de Personas con Discapacidad Visual (AMADIVI). AMADIVI is a private organization whose mission is to provide people with blindness and visual impairment with educational and technological tools to facilitate their access to information, education, and daily life (AMADIVI, 2023).

The *Instituto Mexicano de Oftalmología* (Mexican Institute of Ophthalmology) and the *Hospital de la Luz* (Hospital of the Light) represent Mexico in the International Agency for the Prevention of Blindness. The Mexican Institute of Ophthalmology is a private institute that trains medical doctors in ophthalmology and provides eye care at a low cost (Instituto Mexicano de Oftalmología, 2023). The Hospital of the Light is a private hospital that seeks visual health and self-sufficiency for people with visual impairments through specialized medical services (Hospital de la Luz, 2023). Together they promote medical advances in the country to prevent and treat visual impairments.

In terms of prevention, Mexico, like other countries, face the challenge that visual health is not included in the primary health plan. Thus eye care is not accessible for most of this country's population. Additionally, visual health is not included in educational programmes, and there aren't awareness initiatives in the community about visual impairments, their causes and the way to prevent them.

Regarding treatment, Mexico lacks resources in its public hospitals to provide attention to all people with visual impairments. This country also lacks resources to reach people living in towns nearby who don't have access to visual health. On the other hand, treatments at a private hospital are too expensive for most people to afford, making eye health a privilege.

Another obstacle in treatment is that ophthalmological training doesn't include the emotional impact of sight loss. Related to Thurston's research in the UK (2010), in Mexico, when a person gets a diagnosis of sight loss, their emotions are not held. Once, an ophthalmologist told me he didn't know what to do when a person starts crying after a diagnosis of sight loss.

Additionally, ophthalmological and rehabilitation services are not connected. Therefore, when a person receives a diagnosis of sight loss, they are not referred to rehabilitation services. Getting to rehabilitation depends on the person's initiative or referral from friends and family.

In terms of rehabilitation, Mexico doesn't have a unified guideline for rehabilitation programmes for people with blindness or severe visual impairment. Every state defines their governmental programme. Additionally, in every state, there are charities and private institutions that work independently with their own programmes and regulations.

Along with developing skills such as braille, orientation and mobility and skills for everyday life, some programmes mention offering psychological attention throughout their rehabilitation programmes. However, it is not specified in which way these services are provided, and the framework varies from one state to another. An interesting example is Tabasco, in which the governmental programme for people with sight loss offers psychotherapy alongside thanatology (DIF Tabasco, 2023). This represents a possible unconscious association with blindness and death. These cultural associations are further explored in section 2.4.2.

Concerning counselling and psychotherapeutic services, Mexico faces another challenge. The Mexican Psychological Society developed an ethical code for Mexican psychologists that highlights that to provide counselling or psychotherapeutic services, a psychologist must have a clinical graduate degree (Sociedad Mexicana de Psicologia, 2009). Nonetheless, although this guideline is clear, there isn't an organization that reviews psychologists' degrees to ensure that professionals that provide counselling and/or psychotherapeutic services have the appropriate credentials. Also, this information is mostly unknown by the general population, which also facilitates psychologists without a clinical degree to provide psychotherapeutic services for which they are untrained. Furthermore, as not even basic credentials are checked, some people without a psychology degree pose as psychotherapists in various ways, i.e. coaching, aligning energies through magnets, talking with angels, etc.

Regarding inclusion, in 2011, the General Law for the Inclusion of People with Disabilities was created in Mexico (Diario Oficial de la Federación, 2011). This law mentions that people with disabilities can enjoy all rights established in the Mexican constitution:

- The right to the highest level of health and rehabilitation service possible.
- Equal access to job opportunities that promote personal, social and professional development.

- Equal access to education, prohibiting discrimination in any educational system.
- Right to universal accessibility and household, creating safe transportation and accessibility to public and private locations.
- Access to all transportation, systems, and technologies, particularly those that contribute to their independence and integral development
- Right to higher access to protection and social assistance programmes, including feeding, dressing and household.
- Right to be accounted for in the National Census of Population, providing statistics of people with disabilities to create new programmes and policies
- Right to practice sports and having the government's administrative, technical, human and economic support to do so
- Right to culture and recreational activities, as well as developing their artistic capacities and safekeeping their intellectual property rights.
- Right to proper treatment when undertaking an administrative or justice process, such as counselling and free juridical representation
- Right to freedom of speech, receiving and facilitating information by any means of communication that facilitates their participation in society

The National Council for Development and Inclusion of People with Disability was created to establish public policies and coordinate the public and private sectors to ensure these laws are followed (Diario Oficial de la Federación, 2011).

As in other countries, even though Mexico has established laws that "guarantee" the inclusion of people with disabilities, these guidelines are not implemented.

According to the last Census, 5.7% of the Mexican population has a disability. This number is equivalent to 7 million 168 thousand 178 people. Of this, 5.7%, 19% do not know how to read or write (INEGI, 2021). Additionally, 80 to 90% of people with disabilities are unemployed. Of those employed, 14% are reported to be working without payment, and another 22.6% receive less than the minimum wage (UN, 2023).

Specific statistics about people with blindness or visual impairments show that 51.7% of those with these impairments from between 6 and 29 years don't attend school, while 32.2% of the population with blindness or visual impairments cannot read or write (INEGI, 2021).

Regarding working conditions, 32% of people with blindness and visual impairments older than 12 years old are economically active. Nonetheless, only 1.9% have a professional degree, 2.2% work as specialized technicians, 1.2% are managers, 5% are clerks, 5.3% are domestic workers, 6% work as services providers, 16.6% work at independent sales, 19.2% work as labour force and 26% work at agriculture. Regarding their job position, 42% work as employees or labour force, 34.9% work on their own, 10.8 work as a labourer, 6.6% work without payment, and only 2.2% are bosses (INEGI, 2021)

Additionally, people with visual impairments encounter several social barriers in Mexico regarding accessibility that exclude them and make it impossible to perform everyday activities in an individual, autonomous way. For example, to move from one place to another, a person with blindness would have to use public transportation. Nonetheless, there aren't any non-visual signals at bus stops to know which route they can wait for at that bus stop. Asking the people around them or the bus driver makes the person with blindness dependent on others and is almost always unsuccessful, as people with blindness are constantly ignored. These examples are another indicator of common social attitudes in Mexico that I’ve noticed as a social participant in this country.

Having framed the context in which this study was conducted, next section presents the literature review that was used as theoretical references to build this research.

2.- Psycho-Social Dimensions of Sight Loss: Literature review

2.1 Introduction

As mentioned in the previous chapter, I come from a psychological background. When I started researching sight loss, my aim was solely to understand the grieving process from a psychological perspective. When conducting previous studies (see section 1.2), I started identifying the social obstacles to implementing emotional support for people with sight loss, which led me to include the social dimension in this research.

As previously mentioned, this research aimed to

1. Deepen the understanding of sight loss as a process involving loss, and reconstruction, of identity,
2. Explore the needs and obstacles to implementing emotional support for acquired blindness in the rehabilitation centres in Mexico, and
3. Explore the perception of blindness and where this perception comes from.

Through this chapter, I present the literature review, both from a psychological and a sociological perspective, that guided this project.

Section 2.2 presents the studies conducted by Dr. Thurston, which are key to this research. Dr. Thurston explored the emotional effect of sight loss in the UK. Her research led her to develop the Five Stage Model of Sight Loss, a theoretical model to understand the grieving process of losing sight. Furthermore, based on this model, she consolidated an emotional support protocol for people with sight loss that is now used at the Royal National Institute of the Blind and Retina UK. Following Dr. Thurston's research, this project adapts her methodology to the Mexican population adding a new dimension: psycho-social studies. This research was designed to explore the perception of blindness and emotional support for people with sight loss at the rehabilitation centres for blindness in Mexico to understand the needs and obstacles to implementing this service.

Section 2.3 presents the supporting literature on the psychological dimension of sight loss. Section 2.3.1 elaborates on the definitions of identity and self and the role of sight in identity formation. In section 2.3.2, I introduce the psychodynamic theoretical research I conducted as a thesis for my MSc degree that aimed to deepen my understanding of the grieving process of sight loss as a loss and reconstruction of identity. Finally, section 2.3.3 presents a definition of the concepts of *psychotherapy* and *counselling* to set the conceptual frame in which emotional support for people with sight loss is provided.

Section 2.4 presents the social dimension of sight loss. Section 2.4.1 reviews the concept of the social unconscious and how the unconscious perspective towards blindness from society impacts the sense of belonging and social identity. Section 2.4.2 expands on cultural and historical references towards blindness to provide a broader picture of the unconscious associations towards blindness through time that is still present today. Section 2.4.3 presents the role of language in embedding these unconscious associations in culture. Finally, section 2.4.4. presents the social perspective towards disability and blindness through the lens of the disability models.

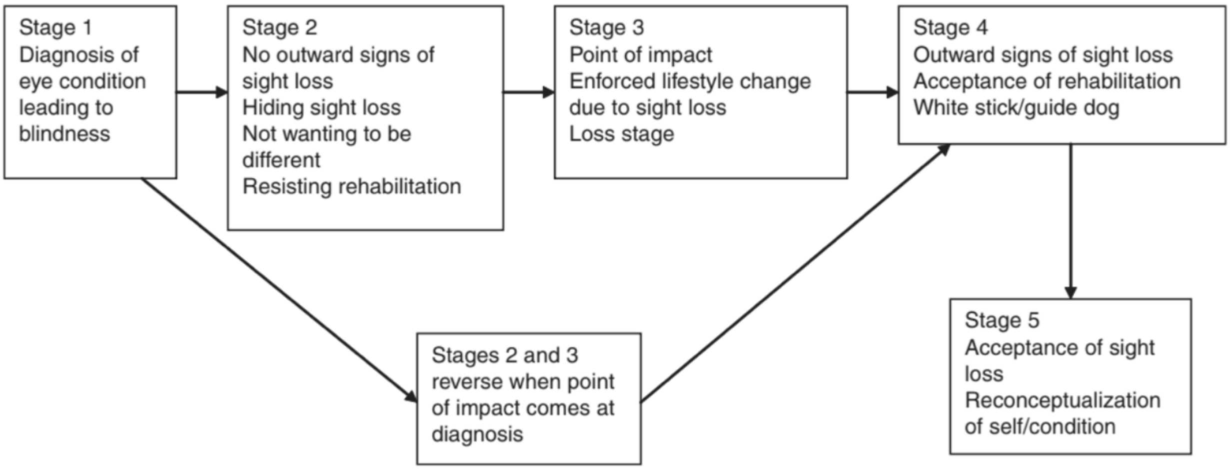
Finally, section 2.5 introduces the psycho-social dimensions of sight-loss in Mexico. Section 2.5.1 presents aspects of Mexico's social unconscious regarding the perception towards people with disabilities. A revision of Mexico's colonization by Spain will be presented as the starting point of these perceptions that were intergenerationally transmitted and are still present today. Lastly, section 2.5.2 presents a study I conducted as part of this programme that served as a first approach to unveil the unconscious perceptions towards blindness in Mexico through the Visual Matrix Method.

2.2 Thurston et al. A key study

This research is based on Dr. Mhairi Thurston's work. In 2010, she, along with Allen Thurston and John Mcleod, conducted a study to examine the socio-emotional impact of sight loss in four core areas: mood, self-concept, social connectedness and loss. The data was collected using the mental health and social functioning subscales of the National Eye Institute Visual Functioning Questionnaire-25 and semi-structured interviews. Eighteen blind and partially sighted adults from the East coast of Scotland participated.

The study results showed reduced mental health and decreased social functioning experienced by the participants. A commonly shared transition was experienced from sight to blindness, starting with diagnosis, coping with sight deterioration, grieving processes and loss, changed perception of self, their experience of others, and experience of rehabilitation. Participants also described a lack of emotional support from the health professionals from whom they received the diagnosis and rejection within society. Overall, this transition was reported as hugely complex and "involving a profound sense of loss and a fundamental challenge to a sense of self as a valued and worthwhile member of the community" (Thurston et al., 2010. Pp 105).

From this study, a theoretical model was proposed to describe the socio-emotional transition from sight to blindness (Thurston et al., 2010. Pp 107):



The first stage defines the moment of diagnosis of an eye condition that leads to blindness. The reactions during this stage typically include shock, panic and disbelief. In the second stage, sight loss signs have not yet appeared, and strategies to hide the condition may be adopted to try to maintain life as unchanged as possible. During this stage, resistance to rehabilitation can be reported. The third stage defines the point of impact where sight loss has affected lifestyle. This stage is characterised by loss, and the emotional reaction is precipitated. During the fourth stage, there can be acceptance of rehabilitation and manifestations of sight loss, such as using a cane. This stage is emotionally challenging as it leads to changes in self-perception and the perception by others. During the fifth stage, acceptance of sight loss can be associated with a reconceptualisation of the self. Renouncing to the possibility of seeing leads to shifting the focus towards the things that can be done and exploring new ways of doing them instead of the loss of sight. The development of new abilities to keep performing everyday activities in an autonomous way leads to the acceptance of blindness and a reconceptualization as a person with blindness. This model is not prescriptive, as all grieving processes are different, but instead proposes a conceptualisation for understanding some of the issues involved in the transition from sight to blindness and advocates for further study of the process of *becoming* blind to develop effective psychological interventions (Thurston et al., 2010).

The grieving process of sight loss implies a renunciation of the ability to see and a reconstruction of identity as a person with blindness. This model, unlike other grieving models for sight loss, is the only one that includes the transformation of identity as part of the process.

I came across Thurston's model while working on my bachelor's thesis (see section 1.2). It resonated with me because it shed light over my experience with my mother: my mother never renounced the possibility of seeing; therefore, she never could adjust to blindness. Since then, I have followed the work she was developing in the UK.

After she theorised the grieving process of sight loss, UK Vision Strategy developed a consultation document named "Seeing it my way" in 2011. In agreement with what Thurston had theorised a year earlier, people with sight loss reported wanting someone to talk to and for that support to be appropriate to their needs.

Hence, in 2013, the first treatment model appeared. A follow-up case study was conducted to examine the process and outcome of counselling for a 70-year-old client who had experienced complete, irreversible post-operative sight loss. The client received six weekly 1-hour sessions from a counsellor accredited by the British Association of Counselling and Psychotherapy and who is registered blind (Thurston et. al., 2013). A pluralistic approach was used in which the client and therapist worked together to identify tasks and methods that can help the client toward their goal. The sessions were audio-recorded. The therapist invited the client to complete the Clinical Outcomes Routine Evaluation (CORE) and the Target Complaints form (TC) orally at the beginning of each session and the Working Alliance Inventory (WAI) and Helpful Aspects of Therapy (HAT) at the end. One week after the final session, the client completed the Clinical Outcomes Routine Evaluation (CORE), the State Hope Scale and the Change Inventory.

Quantitative measures show that although her mean well-being scores remained unchanged, the perception of how much the problem bothered her decreased. Her risk of suicide or self-harm was also reported to decrease during therapy. The aspects of counselling the client reported as most helpful were: feeling understood; being able to express emotions around the loss of sight; finding a new identity, finding ways to cope with fear, loss, dependency and other people's perceptions; exploring the possibility of a future and life purpose without sight; making sense of things; having a blind counsellor. The positive changes reported by the client were: feeling more connected, having a hopeful future and using coping strategies. The suggestions made by the client for the improvement of the sessions were to provide more sessions, involve people with blindness, connect the counselling services to the Royal National Institute of Blind People (RNIB), and offer more guidance and training for carers, including the instrumental and emotional needs of people with sight loss. This study's findings showed that the client experienced positive change after six sessions of pluralistic counselling with a blind therapist. However, it would have been helpful to have more sessions. This study was the first approach towards designing an effective model of counselling for people with sight loss (Thurston et al., 2013).

These efforts led to the creation of emotional support and counselling provided by the Royal National Institute of Blind People (RNIB) in a three-tier framework:

- Tier 1- Information and peer support provided by the eye clinic liaison officers (ECLOs), sight loss support workers and peer support programmes.
- Tier 2- Specialist counselling services to help during the adaptation to sight loss.

- Tier 3- Acute mental health services for people with severe mental health issues as an effect of sight loss.

This framework provides reassurance that there is some emotional support for people with sight loss. Nonetheless, there is still work that needs to be done. Further studies (Thurston et al., 2013; Pybis et al., 2016) show that counselling should be available when needed. For some people, this may be at the stage of the diagnosis, whilst for others, the priority might be learning to live physically with this change, and the emotional impact may not be visible until further on. Other people may need support throughout the journey. Additionally, each person's required support level might differ and change over time. Research also shows that it is crucial to clients that counsellors have specific training regarding sight loss.

As reviewed in section 1.3.2, Mexico doesn't have a unified strategy for rehabilitation services for blindness. Therefore, it lacks the structure to provide access to emotional support for people with sight loss. Some rehabilitation programmes include counselling, while others do not. Furthermore, as this service is not formally required and there aren't any therapeutic guidelines, there aren't training programmes for counsellors for people with sight loss. Mexico is ten years behind the United Kingdom.

Following Thurston's steps (2010, 2013 & 2016), this project explored the needs and obstacles to implementing counselling for people with sight loss in the Mexican population. Nonetheless, as a difference from the mixed methodology used in her studies, this research added a new dimension to this first step of the journey, exploring both the individual and the social experiences of sight loss and emotional support from a psycho-social perspective.

2.3 The role of sight in the identity formation and the consequences of its loss: the psychological dimension

As mentioned in the previous section, Thurston’s Five Stages of Sight Loss model proposes the psychological explanation that for acceptance to be achieved, there must be a renunciation of the previous identity as a sighted person and a reconceptualization of a new identity as a person with blindness.

These sections expand this psychological dimension by reviewing the role of sight in identity formation and the consequences of its loss. Through section 2.3.1, we will review the fundamental concepts of identity and self in relation to sight and blindness and present how these concepts will be used throughout the study. In section 2.3.2, I introduce the psychodynamic theoretical research I conducted as a thesis for my MSc degree that aimed to deepen my understanding of the grieving process of sight loss as a loss and reconstruction of identity. I provide it here as a background of how I understand the psychological dimension of sight loss and, therefore, my psychodynamic theoretical standpoint throughout this project. Finally, section 2.3.3 presents a definition of the key concepts of psychotherapy and counselling to set the conceptual frame in which emotional support for people with sight loss is provided, particularly in Mexico.

2.3.1 Identity, self and sight: developmental and embodied perspectives

To understand Thurston's proposal that a person with sight loss accepts blindness once they have redefined their identity as a person with blindness, we first must understand the concept of identity and the role sight plays in its development. Thus, this section reviews the different ideas on the concept of identity and its development. This revision also sets a frame of reference on how identity is conceptualised through this research.

I want to start by separating two similar yet different concepts: identity and self. Although both of them refer to the definition of one's own person, according to Elliot (2014), there are many forms of social, collective identities that are not related to one's self, such as a national identity. On the other hand, the self is defined by the subjective ways in which we experience the world.

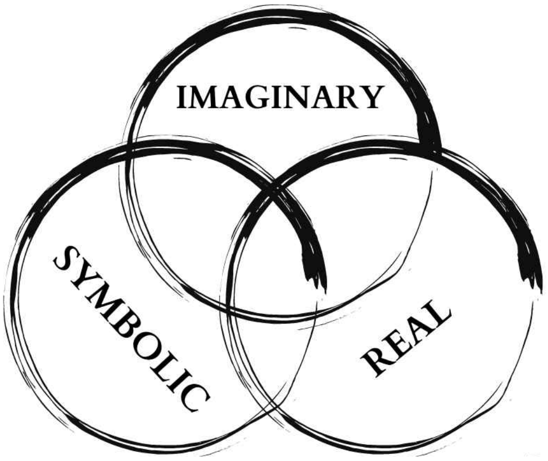
The *self* would then be a unique definition of our inner world and psychic configuration, whilst *identity* adds a social perspective in which the self identifies with external components that become part of one's identity. *The self is identified.*

Neither identity nor self are static. Identity is fluid. The self is flexible, fractured, and fragmented. "The self is a symbolic project that the individual actively and creatively forges" (Elliot, 2014, pp.9)

There is an ongoing debate regarding identity formation between psychoanalytic and sociological theories. Psychoanalytic theories, such as *Three Essays on the Theory of Sexuality* by Sigmund Freud (1905) and Lacan's *Mirror Stage* (1949), emphasise the internal world and emotional conflict in the organisation of identity. Additionally, Donald Winnicott, in his work *Playing and Reality* (1971) and Melanie Klein, in her text *Envy and Gratitude* (1957), elaborate on how that inner world permeates the way the child creates and sustains relationships with others. On the other hand, sociological theories emphasise that our identity is constructed by internalising aspects of the culture of our society. At the same time, we constantly build that society by returning to it our elaborated understanding of the culture surrounding us (Elliot, 2004).

If we return to the previous definition provided by Elliot (2014) of identity and the self, perhaps these two theories are not necessarily independent but could intertwine insofar as the self could represent the inner world, emotional conflicts and desires, constructed indeed by internalising aspects of the first society we live in: our family (in any sense of the word, from the traditional understanding of mother-father-siblings, extended family, same-sex couples, adoption, assisted reproduction, or the family that's made in an orphanage). We cannot exclude the social from the person in constructing that inner world. Later, when the self is presented within the culture outside their family, the self becomes socially identified with the traditions or groups that surround them, which becomes an essential aspect of the identity.

A theorization that considers both the psychological and social dimension in the formation of identity is Lacan's Borromen knot (1953). In this theory, Lacan proposes the interactions of three psychic dimensions (the real, the symbolic and the imaginary) as the representations of the patters of identity formation:



Borromean knot, by Beyond Peace (2020).

The *real* refers to a part of the individual's reality that is never truly known and is impossible to understand. The real can only be thought of with the imaginary and the symbolic. An example of the real order is death, a fact we recognise as part of our reality, but it is unknown and cannot be thought about without considering our imagination of death and the symbolic structure and social associations surrounding it (Lacan, 1953).

The *imaginary* is the realm of images and imagination. The Dictionary of Psychoanalysis defines imaginary as the image constituted in the subject by the reflection of the other or their specular self through the Mirror Stage (Laplanche & Pontalis, 2004, p. 190). In this stage, which happens between six and 18 months of age, the child cannot take control of their body and thus feels fragmented. Nonetheless, when finding a reflection in another human being or their own reflection in a mirror, they recognise that other and perceive a complete image that they lack. Thus, by the jealousy and desire to have that completion, the body is imaginarily unified, and the first draft of identity emerges (Lacan, 1953). From an intrasubjective point of view, the imaginary defines the narcissistic relationship between the individual with themselves. From an intersubjective perspective, it defines the dual relationship created by the image of the other: for the individual, the only one that can exist is the other (the other that is me) because the self is originally the other (by the initial image created by the other) (Laplanche & Pontalis, 2004, p. 190).

The symbolic order refers to the cultural laws that structure the world. The subject is inserted in a society with an established order that is also symbolic. Lacan describes how the Oedipus complex imposes a symbolic structure on sexuality. The subject emerges through the law established by the Name of the Father (the law that separates the imaginary reality created with the mother)—and gains access to the symbolic, to belonging to society, at the cost of symbolic castration. The individual is then ready to accept and adopt the rules that define the function of society. Language is essential in the symbolic order as it establishes a way of communicating laws. Nonetheless, while the signifier (language) is the foundation of the symbolic order, the signified (the concept behind language) belongs in the imaginary (Lacan, 1953). The relationship between the signifier and the signified Will be further elaborated in section 2.4.3.

According to Lacan, the interaction between these three orders represents the patterns of identity formation. The first stage is the imaginary, from birth to six months of age, in which the baby's psyche functions through images, dreams and desires, as they don't know the language yet. During this stage, the infant is one with the mother figure and cannot differentiate between their imagination and the real world. The second stage is symbolic, in which the paternal figure introduces language and rules that help the child understand and belong to the world. The real introduces areas of life that the child cannot understand, as it escapes all symbolisms and images (Lacan, 1953).

Another aspect to consider is whether a more concrete component of our being could be a defining trait of our identity: our body.

Our body plays a crucial role in the formation of our identity and in conceptualising our own self. The body is the vehicle for communication, vital for the self and identity formation at both a psychological and a social level.

Our body provides us with identifiers from birth, such as gender and skin colour. These identifiers define, at least partially, our place in the society we live in. The meaning given to those identifiers can be different in every society. For instance, in the Middle East, women don't have the same rights as men; they have limited to no access to education and financial inclusion and suffer various forms of objectification and sexual violence. In Syria, a rapist is legally allowed to marry a victim. In Lebanon, "sexual harassment" is not clearly defined (Plan International, 2020; Unicef, 2019). Another example is black and brown people in the US, who still face economic disadvantages, segregation, and denial of health care based on their skin colour (Human Rights Watch, 2022).

Furthermore, Loja et al. (2012) explain that identity is embodied differently when a body has an impairment. This embodiment is a result of bodily limitations and inner conceptions. However, it is also shaped by the definition given by society to people with a disability, which is also internalised. This process is further explored in section 2.4.4.

Sight plays a crucial role in the development of identity. The infant's first encounter with the construction of the self is registered through the mother's eyes. The eyes of the mother are the first channel of projections and introjections (Winnicott, 1971). The infant looks up at the mother and sees themselves in her gaze. The eyes act as a mirror that, if not provided, produce a sense of insecurity that extends from oneself to others.

As previously mentioned, Lacan proposes that the formation of the imaginary of the self (the image constituted in the subject by the reflection of others) takes place through the Mirror Stage (Lacan, 1949). In this stage, the child, who still doesn't have motor coordination and can't hold their own body, is filled with anxiety of fragmentation. By finding their reflection in a mirror or another human being that they perceive as a complete image, they perceive the anticipation of a body unity that they recognise as missing. Nonetheless, they identify with this image, and thus their body is imaginarily unified.

Furthermore, the intersubjective relationships that this person will sustain further in their life are marked by the experience of this stage. These interactions will constitute a dual, imaginary relationship in which the self is constituted as an other and the other as an alter ego. In these interactions, the self finds its reflection in the other, reaffirming its identity and unification (Lacan, 1949; Laplanche & Pontalis, 2004).

Lacan didn't specify that the Mirror Stage was exclusively visual. Nonetheless, he describes this stage as the infant constructing an image (the imaginary) by the reflection of the other or their specular self through the mirror (Lacan, 1949). Based on the language of Lacan and the definition of imaginary (Laplanche & Pontalis, 2004, p. 190), it seems that he was considering solely a visual image in the formation of the self. How, then, would a child with congenital blindness construct their definition of self?

Piaget (1936) sets the first stage of development, the sensory-motor stage, from birth to two years of age. Concerning this stage, Selma Fraiberg (1977), a child psychoanalyst dedicated to the study of the developmental differences between sighted children and children with acquired blindness, proposed that congenital blindness produces a sense of abandonment in the child, presenting difficulties in the construction of mental representations and the acquisition of object permanence. After two years, the child can establish a substitution of what cannot be obtained through sight using, for example, the mother's voice and skin as a reality continuum.

In sighted children, visual stimuli are the primary tool in the maternal link to form the self. For example, sighted children recognise the mother's face and mirror her smile while playing (Spitz, 1951). For children with congenital blindness, this is replaced by hearing and/ or bodily sensations that make up for visual functions (Fraiberg, 1977).

Therefore, the *maternal imago* (Winnicott, 1971*)* would be understood as the mother's unconscious idea, independently of whether this idea is formed through visual, auditory, olfactory, or tactile sensations. The imago, defined by Laplanche and Pontalis (2004, p.191), is the unconscious prototype of the characters that orients the way in which the subject internalises others. Therefore, this unconscious image of the maternal figure that will guide the subject in the formation of their self does not necessarily have to be visual. Therefore, the formation of the self doesn't have to be made solely through sight. It is not the eyes of the mother that produce the formation of the self, but the gaze; the *gaze* understood from the notion of *holding* (Winnicott, 1971) as the corporeal attitude from the mother that provides a set of stimuli, not exclusively visual, that support the infant in the development of a self psychosomatically integrated.

For people born with sight and who constructed their identity primarily through visual stimuli, sight loss represents a redefinition of the inner world- the self and the identification within society from a sighted person to a person with blindness. Adapting to sight loss requires a grieving process of the identity constructed as a sighted person and the acceptance and adaptation towards a new identity as a person with blindness. This is a delicate and complex process in which it can be beneficial to have a space to explore the personal meaning that blindness has for whoever is losing it. This space can also provide holding through this delicate re-elaboration, and to explore ways to re-integrate into society.

In some cases, such as with children with sight loss, extending that space to family becomes crucial. As mentioned earlier, the family is the first society from which the child will learn the first rules and associations. Working with families so that the associations of sight loss transmitted to the child become positive will be a determining factor in the way that child will perceive and confront the social challenges that will later be presented in their life. This is further elaborated in section 5.6.

As we move forward, it's important to remember that identity is fluid and ever-changing. Through this research, we will conceptualise identity as the definition of oneself in the intersection of internal psychological forces and external social factors. Considering this definition, the following section presents a psychodynamic review of the grieving process of sight loss as a loss and reconstruction of identity.

2.3.2 Symbolic death: grieving process of sight loss as a loss and reconstruction of identity. A psychodynamic review.

Following Thurston's work (2010, 2013 & 2016), and once we have defined identity, this section aims to deepen the understanding of sight loss and reconstruction of identity from a psychodynamic perspective.

A psychodynamic approach derives from a psychoanalytic tradition. It traces behaviour to its origin and aims to explore the unconscious processes at play and how they affect the present (American Psychological Association, 2023).

I want to start by establishing the differences between a grieving process in congenital and acquired blindness. Congenital blindness refers to people born without sight, whilst acquired blindness (or sight loss) refers to people who lost sight for diverse reasons. Both people with congenital blindness and sight loss go through a grieving process. This process, as in any grieving experience, has a personal meaning related to the significance given to the loss by each person. Nonetheless, the process in each of these conditions has unique characteristics.

Congenital blindness, even though it shows evidence that an organ fails, does not represent the loss of the organ's function and the re-adaptation to its absence. The grieving process in congenital blindness refers to people born without sight accepting having a different condition from those around them. The cortical reorganizations that take place in a child with congenital blindness, if given access to appropriate education, allow abilities to be gained through the other senses that substitute the activities for which a sighted person uses their eyes. Hellen Keller, in her experience growing up as a person with blindness and deafness, addresses that by accepting their condition as different (and not inferior), a child achieves an adaptation and can develop the same abilities as sighted children (Keller, 2018).

For people with acquired blindness, on the other hand, sight has been the sense on which they have relied throughout life. Sight loss can entail a grieving process that involves not only losing the function of seeing and, therefore, the ability to use that sense to perform daily activities, but also the capacity to register being seen by the other (Murray, 2004).

Thus, sight loss can represent a re-definition of identity at several layers:

- The body's functionality
- The capability of mirroring with the other to recognize oneself in the other
- The social perception towards people with blindness that is now embedded in them

The person with sight loss is immersed in a new reality in which the world hasn't changed, but the perception of the world and from the world has changed dramatically (Lampl & Oliver, 1985).

Besides the most known reference of a grieving process (Kübler-Ross & Kessler, 2006), which proposes that the end of this experiences is the adjustment to the new condition and learning to live without what was lost, several authors have theorized models for the specific grieving process of sight loss (Allen, 1989; Hayeems et. al., 2005; Thurston at al., 2010 & Tuttle & Tuttle, 1996). The following table describes the stages proposed in these models:

	1	2	3	4	5	6	7
Allen (1989)	Pre-impact: sight loss has not caused significant changes in everyday life. There is no realisation of the consequences of the loss	Impact: when sight loss is recognised	Implications of loss: awareness of what sight loss means in everyday life	Conscious or unconscious decision to live with sight loss	Adjustment: learning new ways to perform in everyday life		
Hayeems et al. (2005)	Pre-contemplation: the need to change is not yet recognised or the person is not ready to change	Contemplation: reflection of what it means to change from a sighted person to a person with blindness	Preparation: planning and execution of changes in everyday life's activities	Action: finding creative solutions to deal with sight loss.	Adjustment: self-identification as a person with blindness and making changes in lifestyle to regain autonomy		
Thurston et. al. (2010)	Diagnosis	Resistance to rehabilitation, hiding sight	Emotional impact. Enforced	Outward signs of sight loss.	Acceptance of sight loss.		

		loss and wishing things remain the same	lifestyle changes due to sight loss	Acceptance of rehabilitation	Reconceptualisation of self		
Tuttle & Tuttle (1996)	Physical or social trauma: event where there's a realisation that a change is needed to adapt to the situation	Shock and denial: disbelief, detachment and loss of contact with reality	Grieving and retirement: feelings of pain and the general consciousness of being different. Retirement from family and friends	Succumb and depression: "I can't" stage, where emotional reactions can lead to severe depression	Reevaluation and reaffirmation: seeking the meaning and purpose of life and reassessing values and objectives. This assessment leads to a reaffirmation of the self.	Facing and mobilization: Will to define as a person with blindness and wish to accept the new reality	Acceptance of self and self-esteem: recovery of self-esteem as a worthy and valuable person

Some models (Allen 1989; Thurston, 2010 & Tuttle & Tuttle, 1996) start with a "pre-impact" phase, mainly described as a cognitive moment in which there's a realisation that a change must be made, but there isn't an emotional response yet. The second stage of these models, which represents the first stage of the remaining model (Hayeems et al.) is the emotional shock, denial, and resistance against sight loss. At this moment, the model of Tuttle &Tuttle (1996) addresses the emotional response at stages three and four, describing stage three with feelings of pain and withdrawal and stage four as a moment that can lead to severe depression. It's interesting that this is the only model addressing an emotional response as a stage and not through the stages, as the other models do. The rest of the models describe the implications of sight loss. Allen's model (1989) proposes an awareness of the changes that sight loss entails, which can relate to recognising changes in lifestyle of Thurston's model (2010) reevaluation in Tuttle & Tuttle's model (1996) and include both the contemplation and the preparation stages of the Hayeems el al's model (2005). Afterwards, all models propose an acceptance to live with sight loss, defined by Allen (1989) as a decision and by Hayeems et al. (2005) and Tuttle &Tuttle (1996) as an action and mobilisation of the changes that have to be made. All models agree on the adjustment of sight loss as the last stage, addressing the importance of redefining as a person with sight loss in a visual world.

Compared with the rest of the models for sight loss, in which the focus relies on functionality and the process is read through the actions a person going through grief may be performing, Thurston at. als. model (2010) proposes as a final stage the reconceptualisation of the person as a person without sight. This model proposes the importance of providing the person with sight loss with a space to explore how they used to conceptualise themselves along with the meaning sight has for them and how they might rebuild that identity now without sight.

This model resonated with my own experience (section 1.1) and provided an explanation of the endless grieving process I lived through with my mother. My mother could never renounce the possibility of seeing, and thus she could never accept her blindness. She was not able to explore what she could still do or find new ways of doing what she wanted, regardless of her sight loss. Therefore, she was unable to build a new identity as a person with blindness.

Sigmund Freud (1914) defines *mourning* as the reaction to the loss of an object. This *object* can be a loved one, its representation, or an ideal. In psychoanalysis, the emphasis is not on the lost object but on what this object represents. Although this process begins with the loss of an object that seems external to the person grieving, the underlying loss is that of the meaning of that object to the self. The libidinal investment placed on the lost object causes a narcissistic wound and, in a defensive move, can create retention of the object through a hallucinatory psychosis of desire. In mourning, when the sense of reality shows that the beloved object no longer exists, the world is transformed into a poor and empty space until there can be a re-investment in the self, which would later lead to its positioning in a new object investment. This re-investment, Freud said, necessarily requires time, in which, through a psychodynamic process, the definition of what was lost with the object that's now absent would be defined and grieved.

When sight is lost, the grieving process is not defined by the loss of sight but by what this loss represents to each person. Through this process, it's important to avoid assumptions and projections of the meaning of blindness and to explore and address the individual interpretation of sight loss (Thurston et al., 2010). A psychodynamic understanding could aid in exploring and working through what sight loss means to the person and the adjustment that this new condition entails in their lives.

Freud differentiates mourning from melancholia, defining *melancholy* as an identification with the lost object, turning in the self a series of reproaches and a delirious expectation of punishment. The lost object cannot die and is kept alive by the libidinal re-investiture of the self that allows itself to become that object, directing sadistic attacks on the self. There's an unconscious ambivalence of hate and love towards the object, on which the first one insists on untying the libido from the lost object, and the second one fights to safely keep the libidinal position, leaving the self to be unable to access a grieving process. In a melancholic process, it is inferred that an object is lost; however, this loss is declared as a loss of the self (Freud 1914).

In melancholia, the loss of sight is unimaginable to the self as it represents the loss of oneself and everything known to it. To try to make sense of these losses, some people hold on to religious faith to avoid looking at the reality of losing sight (Harper, 1949). "I know that the Virgin Mary will not let me go blind. She will give me her eyes", a woman progressively losing her sight said. Because of her beliefs, she didn't accept any rehabilitation tools that could help her prepare for sight loss (Thompson et al., 2013, pp. 339). In other cases, people may try to find a reason for their sight loss, usually placing this explanation in sight loss being a punishment for them doing or not doing something. This perception can lead to self-reproaches and denigration, which can cause depression (Lampl & Oliver, 1985).

"In mourning, it is the world which has become poor and empty; in melancholia, it is the ego itself" (Freud, 1914, pp. 244). According to Lampl & Oliver (1985), in the face of sight loss, the interest in the world that is now alien is cancelled, and all productivity is stopped as the necessary tools, both psychical and psychological, are not possessed in order to perform the previous activities.

If we apply a Freudian perspective to sight loss, after the realisation of the implications of this loss, all the losses entailed by the absence of sight are precipitated, leading the person with acquired blindness to a depressive state in which it's required to remove all libido from the links with the object that no longer exists; that object that has become the own self, the sighted self. Faced with the resistance to renounce the libidinal position, it is not strange to find thoughts, and even concrete plans, to stop living. Suicide is the attempt to move from one reality to another through death (Lampl & Oliver, 1985). This was exemplified by the experience of a participant in a previous study who mentioned he had a gun under his bed for when we couldn't handle the pain of not being able to see anymore (Thompson et al., 2013). The reality for those who lose sight is that of a sighted person with no possibility of seeing. To be able to move from that reality, one must accept being *a person with blindness*. The desire to die is not far from the desire for adaptation: one must die as a sighted person to be reborn as a person with blindness.

The passage from *being* a sighted person to *becoming* a person with blindness is delicate. It requires a holding space for the person to psychically elaborate this transition, particularly, as Thurston at al. (2010) proposes, during the stage of emotional impact, which can be different for each person.

Although this holding can be provided by a positive social network (Thompson et al., 2013), and the elaboration of a grieving process doesn't necessarily require professional support, the possibility of accessing professional emotional support is crucial for whoever needs or wants it.

The following section elaborates on the different types of professional psychological services to set the framework and relevant aspects to consider when incorporating emotional support services in rehabilitation centres for blindness.

2.3.3 Psychotherapy or counselling: framing emotional support for people with sight loss

The terminology to describe the emotional support provided by a professional is sometimes unclear. For instance, the concepts of *psychotherapy* and *counselling* are often used interchangeably. Nonetheless, there are fundamental differences in both the frame and methodology of these approaches.

Psychotherapy is the process of getting professional help to address specific issues causing emotional distress (American Psychological Association, 2017). There are five broad approaches on how those issues can be worked through:

1.- Psychoanalysis and psychodynamic therapies focus on discovering the unconscious meanings and reasons for the behaviours, feelings and thoughts that are causing distress.

2.- Behaviour therapy focuses on changing abnormal behaviour by teaching and conditioning.

3.- Cognitive therapy emphasises thoughts rather than behaviour, believing that behaviours will follow if a thought is changed.

4.- Humanistic therapy focuses on people's capacity to develop their maximum potential.

5.- Integrative therapy, meaning using elements from different approaches

All these approaches are validated and provide different ways of dealing with a specific issue. There is no better or correct approach. The decision of which method to use depends on the patient's need and how they wish to address the problem. For instance, if a person wishes to understand the origin of the issue, they might seek a psychoanalytic or psychodynamic approach, which might take longer but will address the problem by understanding its roots. On the other hand, if they wish to work through the issue as quickly as possible and eliminate the distress without understanding the cause, a patient might seek a behavioural or cognitive approach.

Counselling refers to a professional providing emotional support through a specific process (American Psychological Association, 2023). The difference between these two concepts is that a psychotherapeutic process focuses on a specific issue, and a counselling service focuses on a current process the person is going through.

The Royal National Institute of Blind People (2023) uses the term *counselling* to refer to the emotional support services a team of professionals provides. Their service and psychotherapists are accredited by the British Association for Counselling and Psychotherapy (BACP). Those interested in taking the Counselling for Sight Loss course for professionals must show evidence that they are accredited psychotherapists.

This course provides a psychodynamic perspective to understand the grieving process of sight loss based on Thurston's Five Stages of Sight Loss (Thurston et al., 2010) and training in addressing the emotional impact of sight loss. The RNIB proposes a pluralistic approach, meaning that a therapist doesn't need specific clinical training as long they have clinical training. They can draw from their own tools to provide emotional support to people with sight loss. The premise, regardless of the therapist's theoretical orientation, is to explore the meaning of sight loss for the person and what the person needs to cope with it.

The direct translation of the term *counselling* in Spanish is *consejería.* This service refers to support and orientation in specific situations, such as academia or addiction. It doesn't necessarily have to be provided by a licensed professional. However, it can also be provided by someone with experience in the subject, for example, a rehabilitated addict that provides counselling for someone in the rehabilitation process.

In Spanish, the term that refers to providing emotional support through a specific process by licensed psychotherapists is *Acompañamiento Terapéutico.* Although there isn't an official translation, the direct translation in English would be *therapeutic companionship. Acompañamiento Terapéutico,* such as *counselling,* refers to the emotional support a licensed psychotherapist provides through a specific process. A characteristic that differentiates this service from a psychotherapeutic approach is that the professional that provides therapeutic companionship goes to the patient, making "the street" the setting, which aims to deinstitutionalise the traditional practice of the patient going to the psychotherapist's office (Rosique, González & Sanz, 2014). This approach draws from a psychoanalytic perspective, particularly object relational and concretely in Winnicott's theory. The therapist's role is to listen to the patient to accompany them in their desire and show the patient, in situ, the different ways of reacting when facing difficulty.

As mentioned earlier, sight loss entails working through the process of grieving sight and accepting blindness. Therefore, as the RNIB established, a *counselling* framework could best address this process because it provides emotional support through a specific process by a licensed psychotherapist.

Long-term psychotherapy should also be available if people with sight loss wish to continue addressing issues beyond their adjustment process. For instance, it has been reported that people with visual impairments appear to have a greater risk of experiencing traumatic events and developing Post-traumatic Stress Disorder (PTSD). In 2022, Bonsaksen, Brunes & Heir conducted a research project in Norway in which they interviewed 736 adults with a visual impairment to explore the prevalence of PTSD in the population with visual impairment in relation to the general population. They used the PTSD Checklist from the DSM-5 based on the most bothersome reported event from the Life Events Checklist for DSM-5. Results show that the prevalence of PTSD was higher among people with visual impairment than among the general population, both for men (9.0%- 3.8%) and women (13.9%- 8.5%). PTSD related to sexual assault was also significantly higher in women with a visual impairment than in the general population (5.2%- 2.2%). The higher risk for PTDS in people with visual impairment was associated with young age, female gender, sight loss (as opposed to congenital conditions) and multiple impairments. This data suggests that people with a visual impairment may be more vulnerable when facing a life event that can lead to developing PTSD. Besides creating and following up on regulations that can protect people with visual impairments and impairments in general), as the Human Rights Model suggests, psychotherapy must be available at any moment in life for people with visual impairments to have a space to elaborate their daily experiences.

There are social aspects that are relevant to consider when thinking about these services in Mexico. First, as mentioned in section 1.3.2, the Mexican Psychological Society establishes in the ethics code that a psychologist must have a Clinical Master's or Specialty degree to be able to treat patients in any form of providing professional emotional support (Sociedad Mexicana de Psicología, 2009). However, there isn't a professional body that requires that professionals providing psychotherapeutic services have a postgraduate degree. There are many cases of professionals with a bachelor's degree or people without any professional degree providing "psychotherapy" without the clinical tools to do so. Additionally, as there is still a stigma to seeking professional emotional support, this information is mostly unknown by non-psychologists. Thus, people seeking professional emotional support may, inadvertently, begin treatment with someone unqualified. Also, hospitals or companies that want to hire a counsellor may ask only for a bachelor's degree. This is not only unethical but dangerous. In Mexico, a psychologist with a bachelor's degree doesn't have the clinical tools required to hold and work through the range of situations and emotions a person may be dealing with.

As working with people with sight loss represents a delicate process that requires the counsellor to provide a holding space to explore the personal meaning and emotional impact of sight loss (RNIB, 2023), this service must be provided by a counsellor that has a clinical license (meaning, in Mexico, a clinical Master's or Specialty degree). Following the RNIB's framework of a pluralistic approach (2023), the clinical graduate degree from the counsellor can be from any psychotherapeutic approach.

Another social aspect to consider is that naming the service of providing emotional support for people with sight loss in its direct translation with the term *consejería* could open the possibility for this service to be provided by someone who doesn't have a clinical license because of the meaning this word has in Mexico. Therefore, the appropriate terminology would be *Acompañamiento Terapéutico*. Nonetheless, this term is often unknown because providing emotional support for people going through a specific process (i.e. a medical condition or a rehabilitation process) is either provided under the term *psychotherapy* by trained or untrained personnel (remember, there isn't a professional body that regulated clinical credentials), or not provided at all. Hence, all professional emotional support in Mexico is usually catalogued under the term *psychotherapy*.

As we move forward, it's important to keep in mind these cultural differentiators in terminology as they played a relevant role in the questions asked to the participants and the results of this study.

After reviewing the psychological dimension of sight loss through the role of sight in the formation of identity, the grieving process of sight loss as a loss and reconstruction of identity, and the frame to address emotional support for people with sight loss, the following sections expand on the social and cultural aspects that surround and impact these internal, psychological processes.

2.4. Perception towards blindness: the role of the social

The previous sections focused on the psychological dimension of sight loss. Nonetheless, as previously mentioned, this dimension cannot be detached from the social and cultural aspects surrounding the internal psychological process.

Hence, the following sections expand on the social dimension of sight loss by reviewing the formation of the social unconscious and unconscious perceptions towards blindness and how these perceptions impact the adjustment process of sight loss. Section 2.4.1 reviews the key concept of social unconscious and how the unconscious perspective towards blindness from society impacts the sense of belonging and social identity. Section 2.4.2 expands on cultural and historical references of blindness to provide a broader picture of the unconscious associations towards blindness through time that are still present today. Section 2.4.3 presents the role of language in embedding these unconscious associations in culture. Finally, section 2.4.4. presents the social perspective towards disability and blindness through the lense of the disability models.

2.4.1 The social unconscious: a shared perception of blindness

Sigmund Freud defined the unconscious as psychic content that is not present in the field of consciousness because it has been repressed (Laplanche & Pontalis, 2004, p. 193). Although his work focused on exploring the individual intrapsychic dynamic, we can find several passages, such as in *Group Psychology and the Analysis of the Ego* (1921) and *Civilization and its Discontents* (1930), in which he goes beyond the individual unconscious to include the relationship between the individual and the culture, and thus proposing in between the lines the possibility of the existence of an unconscious social dimension. The difficulties in comprehending this concept rely on the fact that it is impossible to assign unconscious aspects to a society, but this is made possible through its members, who may share unconscious aspects derived from the same history or social processes. Considering the interrelation between the individual and society, it is practically impossible to separate the social unconscious from the individual (Penna & Amorim, 2015).

Erick Fromm coined the term "social unconscious" in 1960 to refer to the unconscious ways to internalize the social world and the aspects of our surroundings that we are not conscious of (Penna, 2015). Fromm's definition of social unconscious incorporates the notion of a social filter from a Freudian perspective. This filter contains a language, logic, and traditions of what is allowed and what is forbidden in a given culture, and therefore determines which experiences are authorized into consciousness. This filter is specific to each culture and determines the social unconscious. The repression of specific ideas and drives keeps the functionality of society. Thus, the cultural system within that society serves the purpose of maintaining the social unconscious (Fromm, 1992).

Although the concept of social unconscious may be confused with Jung's concept of collective unconscious, these terms have significant differences. Jung (1969) proposed that the collective unconscious had archetypal images, defined as universal psychic ideas present in every person and culture, creating an unconscious connection between all human beings. The social unconscious, on the other hand, refers to the unconscious content of a group of people that belongs to a specific culture and have shared memories (Fromm, 1992).

The individual and the social unconscious share the same characteristics regarding a-temporality. It allows its members to relive and feed relationships and emotions in the present that were experienced in the past. In regressive situations, particularly facing trauma, the unconscious anxieties may reactivate and affect social behaviour (Penna, 2015).

The social unconscious is stronger than the individual, allowing the formation of a shared unconscious with strangers when facing a threat. Therefore, collective responses to traumatic events are an essential part of the social unconscious because they represent a distressing experience that is likely to be transmitted from one generation to another and remain repressed in the group's unconscious (Penna, 2015).

Williams (2021) defines *intergenerational memory* as one created in a shorter term and in a direct way through the relationship of individuals and families. This type of memory involves patterns of attachment and traumatic experiences being transmitted from parents and grandparents. *Transgenerational memory*, on the other hand, is defined as long-term and indirect. It involves a cultural memory, symbolic systems, rituals and embodied memories. If not elaborated and worked through, intergenerational experiences can turn into transgenerational, defining a way of thinking, acting and feeling based on an experience that becomes inaccessible through time, and therefore condemning an individual, or a society, into a repetition which can sometimes be present without a clear understanding of the reason of such ideas or behaviours. These memories weave the social unconscious.

Belonging to a group establishes a social identity in an individual. It creates a sense of belonging and understanding of the self, similar to others (ingroup) and different from others (outgroup). Additionally, it provides a path for individuals to understand their place in the group and the world. When people claim to belong and identify with a group, they tend to take on the group's attitudes, behaviours, and norms as their own (Postmes et. al., 2010). Farris (2011) proposes the term "interpersonal unconscious", which refers to the reality co-constructed through interpersonal relationships and socialization.

Similarly, Foulkes (2012) places the relevance in the "in-between" when working with group therapy. He proposes that a shared and interactive unconscious can be seen between the members of a group. People rely on other group members for information on how to act, feel and respond (Postmes et. al., 2010). The group's perception influences the individual's perception, and the individual perception strengthens that of the group. These perceptions, and thus the group's attitudes, behaviours, and norms, are defined by the social unconscious and transmitted intergenerationally (Penna, 2015).

The social unconscious is a discourse which hierarchically orders other discourses. Without individuals being conscious about it, their beliefs and behaviours are aligned to maintain the social unconscious and thus the function of the culture in which they live in (Penna, 2015). By acting in agreement with these social traditions, the individual finds a sense of belonging to their social identity. If we return to Elliot's definition of identity (section 2.3.1), to maintain this social identity, the individual incorporates the cultural aspects to their sense of self while at the same time returning these beliefs to the society, strengthening the beliefs of the group.

A group, in sociology, is defined as several people who identify and interact with each other. We belong to different groups that have different sizes and characteristics. Presumably, everyone reading this research belongs to the group of homo sapiens but can perhaps have a different national identity, which refers to the sense of belonging to the country they were born in, or perhaps the one they live in. Within that national identity, we may belong to a specific city or community with its particular characteristics. Furthermore, within that community, there may be groups that we belong to that are defined by our physical aspects, our socio-economic identifiers or the activities we like to do (Elliot, 2014).

Each group has social power relations that are also introjected into the psyche and transmitted intergenerationally as part of the social unconscious (Dalal, 1998). These power relations include systems of inclusion and exclusion determined by the group's conscious and unconscious perceptions.

People with blindness and visual impairments have faced social exclusion regardless of the society they belong to. This exclusion is presented in different ways depending on the cultural characteristics, but it is nonetheless present in most societies (World Health Association, 2019). The exclusion of this particular group is related to the perception towards blindness that the community has introjected via the social unconscious and intergenerationally transmitted through time.

The following section expands on cultural and historical references of blindness to shed light over the chain of signifiers from which the perception towards blindness may be constructed, which is still present today and influences the exclusion of people with blindness and visual impairments.

2.4.2 Keku: the god of shadows. Cultural and historical references of blindness

The following section presents a historical and cultural review of the association of blindness through time to shed light over the unconscious perceptions that may be present when thinking about sight loss and that may be influencing the construction and maintenance of the social barriers towards people with blindness.

> In the beginning, when God created the heavens and earth, the earth was a formless void, and darkness covered the face of the deep, while a wind from God swept over the face of the waters. Then God said, "let it be light," and there was light. And God saw light was good, and God separated the light from the darkness. God called the light Day, and the Darkness he called Night
>
> (1 Genesis 1:5).

All narratives on the universe's origin start with darkness and are followed by light. This dichotomy leads to perceiving darkness as negative and as light as positive. Blindness, as a concept, was coined in the Egyptian culture in the year 1534 Bc. The name *Keku* was given to the deity representing darkness and hell. A few years later, in the Hebers papyrus, the name of the God of darkness is transferred to the darkness of the eyes: *Keku* also came to indicate the inability to see. (Von Klein, 1905; Güemez-Sandoval, 2009). The cure for blindness was to pray to the God of the sun, who possessed the divine eye, making the connection between sight, sun, and light (Von Klein, 1905).

In the Ancient Hebrew culture, blindness was considered a synonym for death, presumably because the eyes of a dead person and a person with blindness do not provide a reflection for sighted people to find themselves. In Ancient Hebrew, the same pleas were recited when someone lost their sight and when someone died (Monbeck, 1973).

Blindness can also be considered a punishment (Larrissy, 2007). The first mention of blindness in the legal system established in Ancient Mesopotamia: "an eye for an eye", was written in the Talion Law (lat. *Lex talionis*). This law established that if a free man empties the eye of the son of another free man, his eye will be empty in return (Letelier, 1967). Still until recently, in Pakistan, the law dictated the punishment of burning the eyes with acid to those who take eyesight from another person (Reyes, 2016).

In Sophocles' play Oedipus Rex, Oedipus decides to take out his own eyes, blinding himself as a punishment for killing his father and marrying her mother. When the chorus sings, "better dead than alive and blind", we can get the notion that blindness is culturally seen as the worst punishment, worse even than death (Sophocles, 429 b.C.). This association of blindness being a terrible punishment can lead us to trace a correlation between incest being seen as a terrible sin deserving of the worst punishment: sight loss. Additionally, the fact that he chose to blind himself could also be interpreted as his attempt to 'turn a blind eye' to psychic truth.

On the other hand, Homer, author of The Iliad and Odyssey and classically portrayed as a person with blindness, allegedly is a possessor of divine messages that he can obtain in exchange for his eyesight. To some sighted people, the belief that the inner vision of a person with blindness represents a higher (or divine) power can provoke anguish and exclusion towards the person with blindness for representing something unknown (Larrissy, 2007).

Since the word blindness was coined, it has been associated with darkness, its most terrifying characteristic. Nonetheless, in 2007, Cristina Oyarzabal, an Argentinian psychoanalyst who specialises in blindness and visual impairments, interviewed several people with sight loss to explore how people with blindness imagined and dreamt. One of the interviewees was a girl with sight loss who mentioned that when she saw, she could see colours, and when she closed her eyes, she saw black, but after losing her sight, she saw nothing (Oyarzabal, 2007). As sighted people, we cannot understand this nothingness. Therefore we think about it as darkness.

About 85% of people who are legally blind have some remaining vision and can perceive some light (Williams, 2020). Such is the example of Jesse Dufton, a paraclimber with blindness. In a personal communication I asked him about his vision. He describes his sight as "looking inside a kaleidoscope. I can see something, but nothing useful" (Dufton, 2022). This is just one example of the many configurations of blindness.

Additionally, people with congenital blindness can create cognitive maps from other senses, and people with sight loss can develop a high capacity for memory, imagination, and visualisation. Regardless, its unconscious relation to darkness, evil and hell shapes the perception adopted for blindness by sighted people throughout time and culture (Caldevilla, 2013).

Back in current times, blindness represents a frightening disease. In the US, blindness was ranked as the third major fear, following cancer and heart disease (The Eye Associates, 2023). In the UK, 78% of people stated that sight is the sense they fear losing the most (Fight for Sight, 2023).

In a global survey by Novartis in 2017, 85% of the participants mentioned they fear losing sight the most compared to their other senses. 87% of participants believed that eye exams are essential to prevent sight loss, but only 33% reported having annual checkups with their ophthalmologists (Novartis, 2017). From these statistics, we can interpret that the fear of *knowing* about one's own sight loss is greater than the fear of sight loss itself.

In a study conducted in 2002, Giridhar et. al., explored the fear of being affected by illness and disability, including blindness, and the perceptions towards people with blindness in Andhra Pradesh, an Indian population. To evaluate the fear of blindness, the researchers interviewed the participants about their fear of different conditions, such as cancer, severe mental illness, heart attack, losing a limb, blindness, deafness, inability to speak and paralysis. Then, they were asked to compare their fear of blindness with the other conditions. Participants were asked which condition they feared most: "being blind or being deaf, having paralysis or being blind, being blind or losing a limb, having a severe mental illness or being blind, being blind or having cancer, suffering a heart attack or being blind, and being blind or unable to speak". Results show a 90.9% prevalence of fear of blindness in the urban population and a 92.1% prevalence in rural areas. There was no significant association of fear of blindness related to age, gender and socioeconomic status. Nonetheless, the fear of blindness was also significantly higher for those with any level of education. Fear of blindness was higher in comparison to other illnesses and disabilities, particularly when compared with deafness (Giridhar et. al., 2002).

Furthermore, to explore the perception of people with blindness, they asked participants if they agreed or disagreed with the following statements:

- Blind people have to depend on sighted people to do most of their things
- Blind people can never really be happy
- Not so much should be expected from a blind person
- Losing one's sight means losing one's self

Results show that more than 90% of the participants belonging to the rural study areas agreed with all the statements. The proportion of those disagreeing with the statements was higher (although not significant) in the urban area, particularly with the statement that people with blindness can never be really happy and losing one's sight means losing one's self (Giridhar et. at., 2002). This difference can represent access to more resources, such as rehabilitation services, in urban areas.

These pre-established associations towards blindness often impede sighted people from recognising the person behind the blind eyes. Sighted people can project their associations towards blindness to the person with blindness, only seeing their blindness and not the person. An example of the projection of these associations is found in the experience of Lampl, a psychoanalyst who lost her sight: "Strangers grabbed my arms as I crossed the street, people pushed me into the bus as if I had useless legs, and in the stores, they talked to my companions, as if I was deaf" (Lampl & Oliver, 1985, p.301).

These associations are also portrayed at the RNIB's campaign "See the person, not the sight loss" (2022), their biggest-ever advertising campaign to create awareness on how associations towards blindness can lead to actions that get in the way of people with sight loss living their lives the way they would want to. Through this campaign, the RNIB created videos of Ava, the main character, that follow her through her journey of sight loss from the moment of diagnosis to adjustment. These videos educate the community on what people with sight loss find most helpful in different situations.

Current society tends to privilege sight as the sense through which we obtain most information about the world. Sight has become the sense of belonging to a visual world, from which a person with blindness is excluded not only by their physical condition but possibly alienated by the symbolism that this condition represents to the sighted population. In the language system, sight has become a linguistic sign that has shaped everyday life: "I will see you tomorrow. We will see".

Through this historical and cultural revision, we can point out that a person with blindness can awaken feelings of rejection due to blindness being culturally and historically associated with darkness, death, a divine punishment, or a divine power. The following section presents a review of how blindness has been perceived through linguistic categories to explore the unconscious associations that may have been created and transferred through language.

2.4.3 Blind: someone that wanders in the dark. Semiotic and semantic aspects of blindness

Language has both an individual and a social aspect; one is not admissible without the other. The act of communicating is itself a psychological process where the individual retrieves the representations of the concepts and then transmits them using a physiological process, either by talking or by non-verbal communication. For the communication to be effective, the representation retrieved has to be part of the structure of language, defined as a social product that represents the body of conventions adopted by society. Hence, language is never complete in a single individual but can only exist in a community (Saussure, 1916). In any given form, language has a crucial role in the formation of the unconscious and, therefore, the unconscious associations. In this section, a review of the construction of language and concepts will be presented along with the definitions of blindness created by society and expressed through language with the aim of complementing the previous section and exploring the possible unconscious associations created towards blindness from a linguistics point of view.

As language is a system of signs and a social institution, it is possible to study the role of signs as part of social life. When a language has selected a sign, it cannot be freely replaced by any other. The individual and the community are bound to its language (Saussure, 1916). As Wittgenstein (1961) states, the limits of language are the limits of the world.

Language is timeless. At any given time, it represents an established system and an evolution. It is both an organisation of the present and a product of the past. Both the history of a civilisation and the history of the language itself are intertwined: the community's way of life affects language, and language, in significant part, makes the community. At any given period, language is always an inheritance of the past.

Language is both invariable and variable. The linguistic sign is subject to change as it continues through time, but through its changes, what predominates is the survival of earlier material (Saussure, 1916).

Sigmund Freud proposes in *Civilization and its Discontents* (1930) that the drives must be suppressed for a society to function collectively. Language, as the way of communication within that society, forces the individual to lose part of themselves to be understood. Therefore, when introjecting language to construct the inner world, we internalise social definitions.

Lacan mentioned that the unconscious is structured like a language. This means that the unconscious is made by chains of repressed signifiers. In his theory, he differentiates the signifier as any material that has a meaning (i.e. words or an image) and the signified as the meaning of the signifier. Together, they create a sign to communicate (Lacan, 1953). Nonetheless, for Lacan (as for Saussure), language is not a system of signs but of signifiers that represent another signifier (and thus the chain of signifiers that leads to the unconscious).

Karl Abel (1882) explores the origin of language, tracing it back to the Egyptian culture. In the Egyptian language, many words have two meanings, one of which is the exact opposite of the other. Abel explains that concepts are constructed by comparison; for example, if there was only light, we would not be able to distinguish darkness and vice-versa. Every concept is then the twin of its contrary. Hence, the doubled-meaning words found in the Egyptian language did not have one meaning or the other but presented the relation and difference between the two. These contradictory primal meanings extend to Semitic and Indo-European languages. In modern languages, a word that originally had two meanings separates into two words with single meanings.

When exploring the language of the unconscious through the interpretation of dreams, Sigmund Freud (1910) writes that the contradictions in dreams are remarkable.

Dreams combine contraries into a unity, representing the content and its opposition as one. Therefore, an element of a dream can mean both itself and its opposite. Building from the work of Abel (1882), Freud concludes that the regressive, archaic character of the expression of thoughts in dreams, as the royal way to the unconscious, is deeply related to language development. This relationship can suggest that language, shaped through time and culture, also possesses an unconscious character that is transferred through generations (Freud, 1910).

As reviewed in the previous section, it is in Egyptian culture that the word *blindness* came to exist. The name *Keku* was given to the deity representing darkness and hell. A few years later, in the Hebers papyrus, the name of the god of darkness is transferred to the darkness of the eyes: *Keku* also came to indicate the inability to see. The cure for keku, possibly caused by cataracts, was a plea to the god Horus, who possessed one of the divine eyes that healed ophthalmological diseases, and his counterpart, the goddess Ra, representative of the sun and the light (Von Klein, 1905; Güemez-Sandoval, 2009).

Through time and culture, the definition of blindness has remained associated with darkness. In English, the word *blind* derives from its ancestor *blunder*, meaning someone wandering in the dark (Bolt, 2005).

The Encarta World English Dictionary (1999) provides the following definition:

> **blind**
>
> **blind** [blind] *adjective*
>
> 1. **unable to see**: unable to see, permanently or temporarily
>
> 2. **unable to recognise**: unwilling or unable to understand something, *blind to the consequences*
>
> 3. **uncontrollable:** so extreme and uncontrollable as to make somebody behave irrationally, *blind rage, blind fear*

4. **unquestioning**: not based on fact and usually total and unquestioning, *blind prejudice*

5. **lacking awareness**, *a blind stupor*

6. **not giving a clear view**: not giving a clear view and possibly dangerous, *a blind corner*

7. SEWING **made on the underside of fabric**: hidden from sight on the underside of a fabric

8. **without doors or windows**: without doors or windows, or not enclosing an open space

9. **closed at one end**: closed off at one end, *a blind unused tunnel*

10. **done without looking**: done without looking or while unable to see, *blind taste tests*

11. **done unprepared**: done without preparation or the relevant information, *a blind presentation*

Although the first definition refers to the physical impairment of the inability to see, the rest of the definitions allude to a social construction where *blindness* is used to define the inability to process intense emotions (blind rage, blind fear), ignorance (unable to recognise, unquestioning, lacking awareness, done without looking), concealment (without doors or windows, with information concealed, closed at one end) or uselessness (without a growing point). These associations may speak of the negative perception that society holds towards blindness.

Interestingly, the word *blind* is defined as an adjective with the potential to describe something else rather than as a noun, denoting a person's impairment. Part of the social model of disability aims to change how society refers to a person with a disability, proposing that an impairment is a condition that a person has (a noun) and not the definition of a person (an adjective)—for example, changing the concept *blind* from being a defining adjective "a blind person" towards blindness being a condition that a person has: "a person with blindness".

Language has both a psychological and a social aspect. Through language, social perceptions are introjected to construct our inner worlds, and our unconscious perceptions are projected to construct the outside social world. The semantic origin and historical references of *blindness* have been shaped through language and incorporated into the social unconscious. These unconscious associations (i.e. terrifying darkness, divine punishment or something unknown) can be an obstacle for people with sight loss to adjust to blindness by impeding access to rehabilitation services, emotional support, education, work, transportation, and social venues, thus impeding people with blindness and visual impairments to continue living their lives the way they want to.

As Freud mentioned, only when the subject can question those super-egoic injunctions can a change of perspective be achieved, and social changes can be proposed (Freud, 1914).

After mapping the cultural and historical references of blindness that were consolidated through time through language and may influence the social unconscious, the following section reviews the social perspective towards disability from the lens of the disability models with the aim to shed light over the interlocking dynamic that is unconsciously sustained by society and that creates and maintains the social barriers towards people with blindness and visual impairments.

2.4.4 Ableism, disability, and blindness

According to the World Health Organization (2023), 1.3 billion people have a significant disability. This number translates to 16% of the world, one in every six of us. Several models of disability have been proposed as frames to understand where disability comes from, what it means to society and what to do about it. Each model directs attention to particular elements of disability and defines the political, economic, psychological and instrumental efforts in a society associated with disability (Dirth & Branscombe, 2017).

The Charity Model understands disability as a tragedy. People with impairments are considered objects of pity who have instrumental value for people without impairments to become better by helping them. This model perpetuates dependence and promotes the idea that people with impairments are useless and thus need saving (Masters, 2022).

The Medical Model understands disability as a medical condition needing treatment and rehabilitation. This model is considered dehumanising because it emphasises the medical condition over the person. Additionally, this model presents a dichotomy between right and wrong, understanding disabilities as a pathology and thus subsequently perceiving people with disabilities as defective and inferior to those without a disability (Dirth & Branscombe, 2017).

Barnes and Mercer (2010) mention that Western societies perceive disability as a failure and a tragedy. Although it is not their intention, the medical model of disability is a significant source of prejudice. The medical diagnosis typecasts people within a particular pathology and functional limitations. These diagnoses are accompanied by social ableist perceptions (i.e. disability being a defect that the person must rehabilitate), thus promoting social exclusion by placing the person in an inferior position. Secondarily, the excluded person takes on the " victim " role within themselves and society. On their behalf, Loja et. al. (2012) present that this medical perspective plays an essential role in invalidating the "not normal" bodies as impaired bodies seen as biologically inferior. This perspective is highly politicised as a hierarchy of bodily traits that determines the distribution of privileges: some bodies become more important than others. People with disabled bodies are deemed not to deserve the same treatment as non-disabled people.

Bogart & Dunn (2019) define *ableism* as the stereotype, prejudice, discrimination and oppression towards people with disabilities. In the World Report on Vision of the World Health Organization (2019) it is mentioned that "people with severe vision impairment experience higher rates of violence and abuse, including bullying and sexual violence" (p. 15). According to Loja et. al. (2012), ableism is the series of beliefs, processes and practices that produce a particular body and self-projected image as perfect and "human". Ableism is used as a justification for having better rights or higher status than other groups. Goodley (2014) adds that sexism, disablism, heterosexism and racism are forms of discrimination that emanate from ableism. This system promotes a "typical" human and normalises medical interventions and technological enhancements to maintain the ableist discourse.

Defining what a "legitimate body" would mean has been the core of the disability discourse (Loja et al., 2012). According to Goodley (2014), ableism has created a "normative citizen" that must be emulated and desired. Disability, ethnicity, class, gender and sexuality represent an "Other" to the dominant sameness dictated by ableist normality, the heteronormative man, adult, white European or North American, with high income. When disability emerges, the attempts to maintain this ableist normality by othering anything that does not fit the defined description is exposed. Ableism leads to an ability-based understanding of oneself, including one's own body and the relationship with others of the same species, different species and the environment.

According to Bulhan (1985), from a clinical perspective, the term *abnormality* is defined through five approaches:

1. From a statistical standpoint, as deviating from the norms that define normality as the conformity of behaviours of the majority of society.
2. A subjective distress for which a person would seek professional help.
3. The medical approach to disease.
4. The cultural approach that differentiates the expression of normal and abnormal from one culture to another.
5. The inability to embody the expected ideal states.

If we think about ableism as the portrayal of a specific body as "perfect", then everything outside the *norm* of a society becomes *abnormal* and, thus, a subject of oppression (Bulhan, 1985).

Rösing (1998) suggests that there are three essential concepts to consider when exploring the cultural differences in the construction of disability: stigma, legitimisation, and exchange value. Stigma refers to being marked negatively. With visible stigma, an illness or an impairment becomes legitimate, and legitimate impairment leads to feelings of pity and sympathy. The legitimisation of stigma then leads to the "superior", not-disabled, body to adopt a position of helper and, in most cases, to the person with an impairment to adopt a position of needing help.

In their sociological introduction to exploring disability, Barnes & Mercer (2010) present that in the 1960s, campaigns were initiated in North America, Scandinavia and Western Europe to expose the ableist normality and shift the attention from the marginalisation being caused by alleged limitations in individual "incapacity" towards the "disabling barriers" that excluded disabled people from participating fully in the society.

These campaigns led to the creation of the Social Model of Disability. According to Oliver (2013), the Social Model of Disability establishes that a disabled person is not disabled by their impairments but by society's disabling barriers. A distinction is made between impairment and disability to understand, beyond the physical, the psychological and social dimensions. Impairment refers to the lack or loss of a functioning part of the body, whilst disability refers to the effects of a society that discriminates against those with an impairment. This discrimination appears through attitudes, as well as physical and organisational arrangements. "One is not disabled. One is made disabled" ("Behindert ist man nich. Behindert wird man") was the slogan of the charity Aktion Sorgenkind in Germany (Rösing, 1998). Since the 1980s, the Social Model of Disability has been gaining strength in fighting the ableist normalisation of society.

As an alternative to the social model of disability and in the context of human rights, laws and policies, the Human Rights Model of Disability emerged. This model focuses on the dignity of the human being, placing the individual at the centre of all decisions affecting them and locating the "problem" outside the person and in society. Although this model is considered a departure from the social model, both models are fundamentally similar. They both emphasise the experience of the person and the barriers in society. Nonetheless, the human rights model provides a shift in the discourse from "blaming" society for the limits of inclusion of people with impairments towards stating that everyone deserves human rights and exploring ways to ensure that everyone, regardless of their physical condition, can access them. This discourse provides a framework that can be more easily incorporated into public policies. Thus, this model has been adopted by the UN Committee on the Rights of Persons with Disabilities (Lawson & Beckett, 2020).

An example of this model's effect is the consolidation of the first-ever European framework for action to achieve the highest standard of health for people with impairments, adopted by 53 countries of the WHO European Region at the 72nd session of the WHO Regional Committee in 2022. This framework, set at the highest political level, seeks to remove all barriers to access to health care for the 135 million people living with impairments in Europe and Central Asia through four fundamental principles: people with disabilities should have the same rights as people without a disability; health services should be accessible to everyone, including people with disabilities; health services should consider needs of people with impairment in any stage of their lives; and inclusion for people with disabilities should be integrated into national health systems. "Leaving no one behind means building systems and societies that work for everyone" (WHO, 2022).

The real challenge of changing the system is changing the perception of the people that run the system. The perception and positioning towards people with impairments, and thus the creation of disability, is embedded via the social unconscious and has become part of the functionality of society. Unconsciously, both parties within that society serve the purpose of maintaining these positions (Fromm, 1992). When the system functions in such an interlocking way, we cannot avoid asking, "Who is responsible and who profits?" (Meekosha, 2010)

The answer is both. It is evident how people without a disability can seek to maintain this othering differentiation because it places them in a "superior" position, justifying access to better rights or higher status than other groups. Nonetheless, people with impairments also benefit from this dynamic.

Sigmund Freud (1905) proposed the concept of secondary gain to explain the benefit derived from a physical or mental illness. When a physical or mental illness presents itself, there is the primary gain, which serves the purpose of relieving anxiety and maintaining the libidinal economy, and the secondary gain, which describes the benefits of having that illness. For example, a professional climber is about to compete at the world cup, and suddenly, she finds her knee so stiff she cannot bend it. This symptom allows her to avoid competing, satisfying her desire to escape her commitment without feeling guilty (secondary gain), as she cannot be blamed for her physical limitation (primary gain). For people with blindness, this secondary gain is related to not having to find a job and sustain themselves economically. They, of course, cannot be blamed because job opportunities are not provided. Hence they stay in the position of being objects of charity.

"The benighted traveller may sing aloud in the dark to deny his own fears; but, for all that, he will not see an inch further beyond his nose" (Freud, 1926, p. 96). Thus, to break this system, both groups would have to renounce the gains it represents to each of them and explore a new configuration for the function of society.

Goodley (2014), when writing about Critical Disability Studies, proposes the separation of the study of the coexisting processes of dis/ability and disablism/ableism. Even though ability needs to be present to speak of what is not, disability is constantly haunted by the ability spectrum. When separating ableism and ability, disability emerges not as the not-able, oppressed other but as a resistant alternative to ableism's ideals. Loja et. al. (2012) write about Critical Disability Studies as a movement that fights the ableist normalisation by proposing the politics of difference to destabilise society and legitimate human variation.

In a fight against ableism, 14 global organisations of people with disabilities created the International Disability Alliance. This alliance advocates at the United Nations for a more inclusive global environment and supports organisations of people with disabilities to hold their governments accountable and advocate for change. The cornerstone of their work is the United Nations Convention on the Rights of Persons with Disabilities (International Disability Alliance, 2023).

The Convention on the Rights of Persons with Disabilities from the UN (2006) established eight guiding principles:

1.- Respect for inherent dignity, individual autonomy, including the freedom to make choices, and independence.

2.- Non-discrimination

3.- Full and effective participation and inclusion in society

4.- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

5.- Equality of opportunity

6.-Accessibility

7.- Equality between men and women

8.- Respect for the evolving capacities of children with disabilities and the right of children with disabilities to preserve their identities.

Although these guiding principles should be followed by countries that belong to the United Nations, the ableist perception towards people with impairments leads to attitudes and actions of discrimination, such as lack of access to education, work opportunities and social participation.

In terms of education, there are currently 240 million children living with a disability. This number represents one in every ten children. According to data from UNICEF (2021), in relation to children without impairments, children with impairments are:

- 24% less likely to have access to early stimulation
- 49% more likely to not be able to attend school
- 25% more likely to be wasted and 34% more likely to be stunted
- 51% more likely to feel unhappy and 41% more likely to feel discriminated against

According to UNESCO's 2020 *Global Education Monitoring Report: Inclusion and education- All means all*, less than 10% of the countries in the world have laws that help ensure full inclusion in education (UNESCO, 2020). UNICEF calls on governments to ensure that children with impairments have equal opportunities. For this to be achieved, governments must work with people with impairments to listen to their experience, as well as professionals working with children and several organisations and institutions. The three goals UNICEF is calling upon are that all services are inclusive and accessible, education is inclusive and accessible, and stigma and discrimination are eradicated (UNICEF, 2021).

UNICEF (2021) highlights the relevance of listening to the experiences of people with disabilities. When providing inclusive services, programmes at the community level should be prioritised, such as family-friendly policies that allow for home care and educational settings. They also emphasise the relevance of providing integrated mental health support services into healthcare. Lastly, they promote protection against violence and abuse, preventing neglect and harm to children with disabilities.

Regarding work opportunities, although data on employment of people with disabilities per country is hard to find, it is well-known that people with disabilities share the same difficulties in finding employment everywhere. Globally, 50-70% of people with disabilities of working age in industrialised countries are unemployed. By contrast, this number increases to 80-90% in developing countries (United Nations, 2023).

People with disabilities are frequently not considered employable because of prejudice and limited understanding and acceptance of disability. As reviewed in section 2.4.1, each country has a different social unconscious with specific perceptions towards people with impairments. Nonetheless, all countries share the same outcome: limited inclusion for people with impairments in the workforce.

Some perceptions that prevent companies from hiring people with disabilities are that they create problems in the workplace (South Africa), they cannot do their job effectively (United States, Singapore), they are deemed incapable, unambitious, and not reliable (United Kingdom) and fear of costs of becoming disability-friendly (South Africa, Thailand) (United Nations, 2023).

As a reply to these perspectives, the United Nations establishes that people with disabilities want and should have a dignified and productive life, employment provides income and social participation, and spending on facilities for people with disabilities is not a privilege but an investment every company should do (United Nations, 2023).

Some countries provide benefits from the government to people with disabilities, such as income or discounts in healthcare, groceries, transportation or housing. These benefits vary from one country to another. For instance, in the UK, there are several benefits that people with disabilities can apply for at any stage of their life. This country has a Disability Living Allowance for children under 16 years old, a Personal Independence Payment for adults of working age, a State Pension, an Attendance Allowance for people in State Pension who need someone looking after them, Employment and Support Allowance if the registered disability is incapacitating to continue working, and Carer's Allowance if someone is needed to provide care at home. Additionally, people with disabilities can apply for exemption from paying vehicle tax, parking benefits, disabled person buss pass or railcard, help to buy or lease a car and accessing grants for housing, getting special equipment for work, mental health support or communication support (Government of United Kingdom, 2023).

In contrast, Portugal has a disability pension determined by the beneficiary's social security contribution record and registered earnings (European Commission, 2023). This scheme is also the case in the United States, where the Social Security Disability Insurance (SSDI) provides income for the person registered with an impairment and a family member. Nonetheless, the person with a disability has to have worked for a particular time and earned Social Security work credits to be eligible (United States Government, 2023). This regulation places people with disabilities in an impossible situation in which they cannot access a job to earn credits, and therefore they are not eligible for governmental support. Regulations for someone born with a disability or having a child or children with an impairment are unclear.

When framed appropriately, governmental aid minimises social barriers by providing different types of support for people who cannot sustain a job and therefore do not have access to a stable income to live. Nonetheless, this support is also associated with lower participation in the labour force as some people with disabilities choose to settle for receiving that benefit even though they might be able to work, even if with some limitations (Crudden et. al., 2022).

People with impairments also tend to leave the workforce earlier than people without impairments. Working longer has been associated with living longer because of the sense of usefulness in society. On the contrary, early retirement has been associated with poor mental health and higher mortality risk. Thus, people with impairments who retire early are at risk of financial instability, mental health problems, and death (Crudden et. al., 2022).

Although the guidelines for educational inclusion for children with disabilities and work inclusion for adults with disabilities are clear by global agencies such as UNICEF and the WHO, each country must accept those guidelines and design an implementation strategy that could work, taking into consideration specific social factors.

In addition to the specific social perceptions of every community, each impairment has unique social perceptions and particular barriers. Although people with blindness and visual impairments share the same obstacles as people with other impairments (lack of general inclusion), as reviewed through sections 2.4.2 and 2.4.3, this exclusion is related to the perception of blindness being something terrible. As mentioned in sectionn1.3.1, fighting against this exclusion, the World Blind Union is the global organisation that represents the 253 million people with blindness or partial sight at the United Nations. The Strategic Plan 2022-2025 of the World Blind Union has the goal of affecting global changes that enable the full participation, autonomy, and freedom for people with blindness and partial sight by providing support to its members to implement frameworks for country-level changes (World Blind Union, 2021) The World Blind Union is one of the founding members of the International Disability Alliance (World Blind Union, 2023).

The fight against the ableist normalisation of sight can be personalised through Evgen Bavcar. Bavcar is a photographer who lost his sight before the age of 12 in two consecutive accidents. At 16, he took a camera to picture the girl he loved. He recalls feeling pleasure in the understanding that he could have something that did not belong to him, possess something that he could not see. In a book written by the psychoanalyst Benjamin Mayer- Faulkes (2014), Bavcar describes that he addresses the relationship between the visible and invisible worlds, bending the established perception between sighted people and people with blindness. Creating images that make blindness visible to sighted people, Bavcar presents his conceptual knowledge of the visual world through his pictures. By wearing transparent eyeglasses, Bavcar also challenges sighted people's imagination and the reinforcement of the identification of people with blindness with their physical condition by wearing sunglasses. Wearing transparent eyeglasses, he presents the idea of belonging to the same world as sighted people. Defined by Mayer-Faulkes as "the most elegant of Bavcar's gestures of displacement", it is a small mirror that he carries on his lapel, as he knows that seeing demands the desire to be seen in return. Since he cannot return the specular gaze they are used to, he provides the mirror for those around him to find themselves and feel reassured.

Both Loja et al. (2012) and Oliver (2013) share the view that a significant critique of the social model of disability is the sole focus on social processes, ignoring the biological and mental elements always present with impairment as it conceives the impaired body as a regular, able body. This proposal leaves the conception of the person with a disability only as subject to social values and physical arrangements that define their role in society.

According to Anastasiou & Kauffman (2013), the dichotomy between impairment and disability leads to "body-only" and "society-only" theories that exclude the psychological aspects of impairment. Body impairments are also a painful psychological reality that is constantly overlooked, as written by the psychoanalyst Lampl in her experience of sight loss:

> “In the lonely weeks in hospitals away from home, I had my darkest hours, dreading the prospect of total permanent blindness. I was being cared for by doctors, nurses and other professionals, all of whom seemed to be genuinely interested in my physical healing, but no one ever seemed to wonder how I felt about losing my sight” (Lampl & Olivier, 1985, p. 301).

The lack of recognition of the psychological processes accompanying a bodily impairment is a disabling factor that influences the grieving process. As mentioned in section 2.3.2, sight loss represents a physical loss and entails an emotional grieving process as a loss of the definition of their identity as a sighted person and the construction of a new identity as a person with blindness (Thurston et al., 2010). Additional to the barriers that limit the participation of people with impairments in society (i.e. accessible public transportation, access to education or job opportunities), the lack of recognition of the emotional impact of sight loss is in itself a social barrier as it impedes access to emotional support to whoever wants or needs it throughout this process. Furthermore, if a person with sight loss is emotionally struggling to adjust to blindness, they will most likely not be able to find ways to continue doing their activities and thus continue having a place in society.

This lack of recognition also resonates with the RNIB's campaign "See the person, not the sight loss" (RNIB, 2022), which invites society to reflect on the way they see people with blindness and visual impairments and challenge pre-established perceptions to learn new ways to approach them.

However, why is there a reluctance *to see* people with blindness?

When I was a little girl living with my mother, we would not look at each other when we talked to each other. Since she could not see me, it did not matter where I was looking at. I listen with my ears and talk through my mouth; why would I need to have visual contact with someone I am talking to? My friends at elementary school grew up with me and knew my mother, so it was normal for them that I did not see them when I talked with them. After my mother died, I started living with my aunt and uncle. During the first months I lived there, my aunt would get enraged with me because I did not look at her when she talked to me. I genuinely asked her why I needed to look at her, and she got even angrier, calling me disrespectful. Months later, I started high school on a bigger campus with many more people and couldn't make friends. People would not talk with me. I realised that people needed to be seen in a way I did not know how to see them. I then started practising and noticed I sometimes saw people too intensely, and they backed away. Sometimes I would see them too lightly, and they thought I was not paying attention. After a year and a half, I learned how to see people and started making friends. They eventually told me they were afraid of me because of how I looked at them.

I was caught up in trying to understand why people needed to be seen when talking with them beyond the explanation, "you are not paying attention if you are not looking at me." I never felt a lack of attention from my mother, and she had my full attention when we were talking, even if we were not looking at each other. There had to be another unverbalized meaning in this action.

As mentioned in section 2.3.1, sight plays an essential role in the formation of identity. For someone born seeing, sight becomes the main channel of projections and introjections. This sense is used throughout life as a mirror with others that provides a reaffirmation of their own identity (Winnicott, 1971). A sighted person unconsciously needs to be visually recognised by the other as an exercise to recognise their identity constantly. If this reflection cannot be provided, it could be unconsciously perceived as an attack manifested as the reluctance to be recognised by a person with blindness in the way sighted people need to be recognised: visually.

Once I heard a psychoanalyst who worked as a therapist at a rehabilitation centre for blindness talk at a conference. She mentioned feeling enraged for not being seen by her patients and, therefore, not feeling recognised as a counsellor (Ponder, 2016).

This reaction sheds light on a possible explanation as to why sighted people reject people with blindness. Although the ableist perception towards a body with an impairment and the maintenance of a superior-inferior dynamic is present, perhaps the underlying reason relates to a defensive reaction by sighted people because of the rejection they feel from people with blindness, who cannot provide the recognition they need via a visual gaze.

The social model of disability proposes that once the social barriers are removed, the disability itself is eliminated (Loja et. al., 2012). Nonetheless, for the social barriers to be removed, first, we need to understand why they were built and what purpose they serve in maintaining the specific society's functionality. Having this information, perhaps a different fight against the ableist perspective can be proposed, taking into consideration the unconscious rejection reaction of sighted people towards people with blindness and visual impairments and working through that reaction to make them participants in a change of perspective.

Next section elaborates on the psycho-social dimensions of sight loss in Mexico with the aim to shed light over the social unconscious and the perceptions that maintain the social barriers faced by people with disabilities, particularly blindness and visual impairments, in this country.

2.5 The Psycho-social dimensions of Sight Loss in Mexico

As previously mentioned, after reviewing the psychological and social dimensions of sight loss independently and considering the context presented in section 1.3.2, this section delineates the psycho-social dimensions of sight loss in Mexico. Section 2.5.1 presents a revision of the literature on Mexico's social unconscious regarding the perceptions and norms towards people with disabilities, particularly blindness and visual impairments, that can be traced to Mexico's colonisation by Spain. Then, section 2.5.2 presents the first approximation I made to explore the perception towards people with blindness in Mexico from a psycho-social perspective through a study using the Visual Matrix Method.

2.5.1 Mexican social unconscious: Colonialism and Disability Models

The social unconscious ideas in the Mexican culture regarding the perceptions and norms towards people with disabilities can be traced to Mexico’s colonization by Spain.

In 1519 Hernan Cortes arrived to America to conquer the land and find the treasures of indigenous myths. On his path to Tenochtitlan (the capital and strongest settlement in Mesoamerica, home of the Mexicas), he was aided by various tribes who made alliances with the Spanish to get rid of Moctezuma, the *huey tlatoani* (leader) of

Tenochtitlan (Cuervo, 2016). Days after his arrival, he captured Moctezuma and held him hostage as a bargaining chip with the Mexicas, seeking their surrender. The violence grew until Moctezuma was murdered in June 1520. From then on, the empire of Tenochtitlan began to crumble until it ultimately fell to the hands of Cortes on August 13th, 1521. The Spanish renamed Tenochtitlan Mexico and the reign as *Nueva España* (New Spain) (Gobierno de Mexico, 2019).

Frantz Fanon was a French psychiatrist who dedicated his life to social justice, mainly (and passionately) writing and fighting against oppression and racism (Bulhan, 1985). He described colonialism as an economic oppressive process covered in a racial discourse that serves as an explanation for the uneven division of resources (Fanon, 1967).

Religion was a crucial aspect for the Mexicas. Their religious beliefs defined their culture and their daily actions. The Mexicas were polytheists, considering Quetzalcoatl as the supreme god that represented the duality of humanity as both human and divine. They also believed in Tlaloc (god of the rain) and Huitzilopochtli (god of the sun), to whom they performed human sacrifices every night to ensure the presence of the sun the following day. They build the *Templo Mayor*, which was considered the most prominent building in the sacred enclosure with 25 temples that emulated the mountains, representing the ascension to heaven (Cuervo, 2016).

Knowing how vital their gods were to the Mexicas, the Spanish used religion to colonize them. They promoted the discourse of "civilizing" the natives, saving them from the ungodly pagan rituals that the Spanish considered the human sacrifices to be.

Through this fantasy, the Spanish placed themselves as the superior race. This process is named by Hernandez de Tubert (2021) as the myth of the conquest.

To force the Mexicas into Catholic practices, the Spanish looted the Mexica's temples and destroyed the pyramids and monuments connected with their traditions and memories. They built churches on top of the ruins using glass floors so the Mexicas could see the remnants of their temples (Cuervo, 2016). This sight was a reminder of what could happen to them if they were caught performing their "pagan and ungodly rituals". The Catholic Cathedral still stands today in Mexico City (the previous Tenochtitlan) with glass floors through which people can see the ruins of the Quetzalcoatl temple and the Temple of the Sun. Besides the Cathedral, the ruins of the *Templo Mayor* are now a museum through which people can learn about the pre-Hispanic gods.

In 1531 the image of the Virgin of Guadalupe appeared as the Mexican representation of Christ's mother. The myth mentions that the Virgin appeared to Juan Diego Cuauhtlatoatzin, an indigenous person, at the Tepeyac mountain. She ordered him to go to the bishop and ask him to build a temple on that mountain. Juan Diego had some flowers with him that he carried on his mantle. When he went to see the bishop, he let the flowers fall, and, at his mantle, the image of the Virgin appeared. This was taken as proof of the myth's veracity (Wobeser, 2013).

Virgin of Guadalupe, Marcos Cipac de Aquino (1523-1556)

The image of the Virgin of Guadalupe is filled with symbols for the Mexicas. The Virgin has darker skin like theirs (contrary to the Spanish and European images of the same Virgin, which has whiter skin). This made it easier for the Mexicas to identify with the image. Her hands, joined at prayer, are one darker and another lighter, meaning the union of both races. This union was also represented by the brooch she carries at her neck, identical to the jade that the statues of the Mexica gods had at their chest, which symbolizes their soul, but with a Christian cross engraved as a symbol of life. She also has loose hair, a symbol of virginity to the Mexicas. The black belt means she is expecting a baby. The rays surrounding her symbolize the sun, the god the Mexicas pray to every night with their sacrifices. The rays appear stronger at the height where the baby is to symbolize that he is the sun, the ultimate god, Jesus Christ. Her mantle is covered with stars, just as the mantle given to the *tlatoani*, symbolizing novelty and the importance of whoever bears it. It is also covered with the *nahui ollin* flower, the symbol that represents the presence of god to the Mexicas. At the feet of the Virgin, there is an image of the moon, a representation of the word Metz-xic-co, which means "at the centre of the moon". Also, at the bottom of the image, there is an angel with eagle wings, symbolizing the eagle that marked the signal Huitzilopochtli gave to the Mexicas to build Tenochtitlan (Diocesis de Tepic, 2014). The Spanish carefully constructed and gave the Mexicas a symbol to identify with that would lead them to pray to their god, Jesus Christ.

The Catholic religion became so embedded in the Mexican society that, paradoxically, 300 years later, in 1810, Miguel Hidalgo y Costilla (a Catholic priest) reunited under the image of the Virgin of Guadalupe the strongest army that Mexico has seen through time to fight Spain for the independence of Mexico (Gobierno de Mexico, 2019).

Mexican independence flag, by Miguel Hidalgo y Costilla (1810)

Since the Spanish colonization and until now, Mexico has devotedly adopted the Catholic religion. Most people who believe in the Catholic god are unwilling to question their beliefs because of a profound fear of punishment by god if they dare question his existence or decisions. Perhaps that fear is unconsciously related to the punishment by death from the Spanish to those who did not adopt Catholicism.

Religion was intertwined with medicine for the Mexicas. Sickness was believed to be a punishment from the gods. The Mexica medicine was divided by religion, magic, and empirical knowledge. The *tictl,* who conducted the treatments, was simultaneously the healer, magician, and priest. As the *tictl* was placing the herbs, plants, or animals used as a remedy, they would also be summoning a God through prayers and telling the patients the rituals and offerings they needed to make to be forgiven. If those prayers were not said, the treatment did not work. The magical property was the effects of the plants or animals that were activated through the prayers. (Aranda et al., 2003).

The Mexicas called people with blindness *ixpopoyotli*. The treatment for eye diseases was called *ixpatli*. It consisted of eye drops made with several roots, breast milk and water distilled from roses and mixed with sugar (Neri-Vela, 2016).

As with any other treatment, these *ixpatli* were accompanied by prayers. The following is an example of a prayer used for someone with pain in the eyes:

A vosotros digo, una culebra (a las venas),
Dos culebras, tres, cuatro culebras
Porque maltratáis así el espejo encantado (los ojos)
Y su encantada faz o tez
Id a donde quisiéredes, apartaos a donde os paceriere
Y si no me obedecéis, llamaré a los naguas y huipil de piedras preciosas
Que ella os desparramará y divertirá
Ella os arrojará desparramándoos y os dejará desparramados por esos desiertos
(Neri- Vela, 2016).

To you, I say, one snake (to the veins)
Two snakes, three, four snakes
Because you mistreat the enchanted mirror (the eyes) this way
And its enchanted face and complexion
Go wherever you wish to, back off wherever you want
And if you do not obey me, I will call the *naguas* and *huipil* of precious stones
She will scatter you and enjoy herself
She will spread your pieces and leave you through the deserts

Ruiz de Alarcon, a Spanish colonizer who arrived with cortez in 1520, experienced watching the treatment for blindness from the Mexicas. He wrote in his journal that the Mexicas attributed the soothing effect of the eye drops to the prayers, a superstition that made them brute and ignorant of god's mercy (Neri- Vela, 2016).

Religion and medicine were also intertwined for the Spanish. They also believed diseases were a punishment from god, and prayers accompanied their medical treatments. The only difference was that the prayers were made to a different god. Apparently, praying to the native gods made the Mexicas brutal, but praying to the Catholic god was educated.

When they started to know the Mexica's medical treatments, the Spanish adapted indigenous concepts to the European language to include them in the *Libellus de* *medicinalibus indorum herbis*. This book held all medical treatments from the Spanish, later renamed *Códice de la Cruz-Badiano* (Aranda et al., 2003). First, they criticised the Mexica's medical treatments, and then they appropriated them, changing the name of the god the prayers were directed to.

In 1524, Hernan Cortes inaugurated the first hospital in Mexico, *Hospital de Jesús* (Jesus Hospital). This hospital used Mexica's medicine but prayed to the Catholic god. The hospital had a church inside it so people could pray to god for the recovery of their loved ones (Sandoval et al., 2016). Until today, private hospitals in Mexico are built with a catholic prayer room.

Interestingly, all private hospitals in Mexico have pastoral services, meaning that, if requested, a priest can go talk with the sick person or their families and bring them "the word of god". Nonetheless, hospitals don't hire professional emotional support services. Emotional support is believed to be provided by religion.

As with sickness, the Spanish also believed disability was a punishment sent from god. The inauguration of the Hospital de Jesus marked the beginning of the Charity Model of Disability in Mexico. As mentioned in section 2.4.4, this model identifies disabilities with imperfections, impurities, the rage of gods and the expiation of sins. On the one hand, the Charity Model of Disability has the Christian discourse of compassion and, on the other, exclusion and punishment as people with disabilities were perceived as sinful, useless, dangerous and unnecessary. The *marginalization sub-model*, promoting segregation and abandonment of people with disabilities, is part of the charity model (Sandoval et al., 2016).

Other disability models have also been present throughout time in Mexico. More than 300 years later, in 1857, church and government were separated, giving way to the arrival of the *medical/rehabilitation* disability model. This model promoted a law reform that placed all charity centres in control of religious institutions as the property of the Mexican state. This model discards the spiritual cause of disability in favour of scientific aetiology and medical treatment. Disability is considered a deficiency, alteration or bodily failure and a person with a disability can be useful given the tools to rehabilitate and integrate (Sandoval et al., 2016).

Lastly, the *social period* began in 1999. During this year, the General Assembly of the Organization of American States adopted the Inter-American Convention on the Elimination of All Forms of Discrimination Against People with Disabilities. Additionally, the Mexican Official Standard NOM-173-SSA I- 1998 for the Comprehensive Care for People with Disabilities is enacted by the Mexican Federal Government. This period is characterized by disability not being a religious or medical matter but a result of society designed to meet the needs of "normal" people only. At present, this model is facing several difficulties, such as the lack of a legislative framework that includes all aspects of the Convention of Rights for People with Disabilities and of a national accessibility plan, as well as a low employment rate of people with disabilities and a lack of updated statistics on people with disability and their information and needs (Sandoval et al., 2016).

These three disability models, even though roughly located through time, are not just present in successive historical periods. Given that the Catholic religion is firmly embedded in the Mexican population, the Charity Model is still the most prevalent in this country. From this model, we can still find the stereotype that identifies a person with a disability as an object of charity, forced sterilization on girls and women with a disability without their consent, and social exclusion (Sandoval et al., 2016).

Placing people with disabilities as the object of charity facilitates a superior-inferior dynamic in which people without an impairment see themselves as saviours, while people with impairments adopt a position of needing saving. This dynamic, in

Mexico, represents the colonizing dynamic between the Spanish and Mexicas embedded through the myth of the conquest (Hernandez de Tubert, 2021).

Recent global perspectives incorporated the role of colonization and colonialism as a disabling and devastating experience for the colonized (Meekosha, 2010). Colonialism, as mentioned by Fanon, is an oppressive dynamic that entails an uneven distribution of resources (Fanon, 1967). This uneven distribution of resources is represented in Mexico's healthcare system. The public healthcare system lacks the resources and workforce to provide services to the Mexican population that cannot afford private care. Private care, on the other hand, is accessible only to 10% of the population (Inegi, 2021). Lack of access to health care is a crucial factor that facilitates the development of impairments. In Mexico, health care is a luxury.

Fanon also highlights the racial discourse embedded in colonialism (Fanon, 1967). It is not uncommon to find between those who can afford private health care mostly people with whiter skin and Spanish-European last names, potentially descendants of colonizers. On the other hand, people with darker skin and indigenous last names are more likely to be found in public health care or without access to health care whatsoever.

Additionally, the superior-inferior dynamic has been so embedded in the Mexican culture since the Spanish conquest that it seems that its members unconsciously maintain it by accepting and internalizing their position. *Internalization* is a term that refers to "the process by which external, socio-historical reality is assimilated into internal and subjective reality" (Bulhan, 1985, p. 196). Furthermore, e*pidemialization,* a concept coined by Frantz Fanon, refers to the profound transformation in the acceptance of this subjective inferiority. Fanon develops this concept in relation to skin, but we can draw from this concept to include not just the skin but the body.

As with any other impairment, blindness and visual impairments are not excluded from this reality in Mexico. As mentioned in section 1.3.2, in Mexico, people with blindness and visual impairment face several obstacles.

In terms of prevention, eye care is not included in the primary healthcare plan, meaning preventive check-ups are not available for the general population but only to those who can afford it through the private healthcare system. This factor facilitates the development of visual conditions.

Between 40 and 50% of the cases of people with blindness in Mexico are due to cataracts (INEGI, 2021), a condition that can be cured with surgery. Nonetheless, that surgery is not accessible to everyone.

Additionally, medical and rehabilitation services are not connected, making it impossible for people diagnosed with blindness or severe visual impairment to access rehabilitation services if they don't know the service exists beforehand. If they get to these services, the focus is placed on developing skills such as braille, orientation and mobility and the use of technological tools, which are essential for adjustment; nonetheless, emotional support is either unavailable or provided by untrained personnel. Furthermore, even after undertaking rehabilitation and gaining the skills needed to adjust to blindness or a visual impairment, access to education and jobs is limited, and mobility and accessibility in everyday life are almost impossible.

The history of colonization of the Mexicas by Spain tells us that for a change in culture to happen, instead of imposing a new idea, the idea should come from within the culture (like the myth of the Virgin of Guadalupe). Nonetheless, for an idea to be implanted in a society, it is first crucial to understand the current perception and the role that idea plays in the social unconscious.

As part of the PhD programme, and as a first approach to exploring the social unconscious towards blindness in Mexico from a psycho-social perspective, I conducted a study in which I explored the perception of blindness in students from the Psychology programme of a private university in Mexico. The following section provides a summary of the study and a reflection on how it contributed to this research.

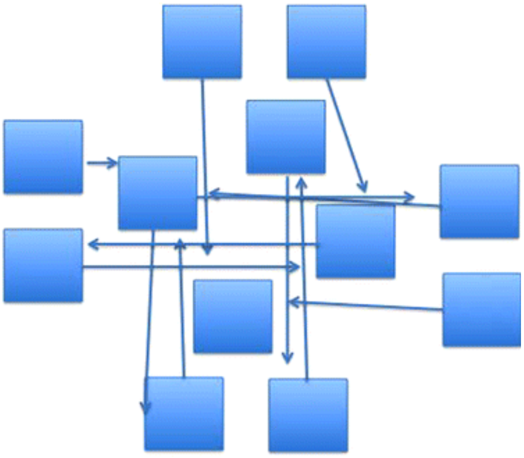
2.5.2 Seeing blindness through the visual matrix: a first approach

This section presents a study I made as part of the "Researching Beneath the Surface" module undertaken for research credit as part of the PhD programme. This study explored the unconscious associations towards people with blindness (the social unconscious) by sighted people through the Visual Matrix Method. The complete details of the study can be found in appendix 9.1.

Method

The Visual Matrix Method aims to understand the unconscious images that are linked with affect. This method, developed from the Social Dreaming Method, drops the emphasis on dreaming but keeps the imagery in the mind and free association (Froggett, Manley & Rosy, 2015), with the main focus on the expression of affect through shared unconscious visualisations (Manley, 2018). The meaning emerging in this interaction, at this particular moment, will not necessarily come in words, as sometimes "words are not enough" (Manley, 2018, p.97).

Nineteen students from a private university in Mexico participated in the study. After looking at the pre-matrix stimulus material (see appendix 9.1), participants were arranged in the snowflake seating arrangement.

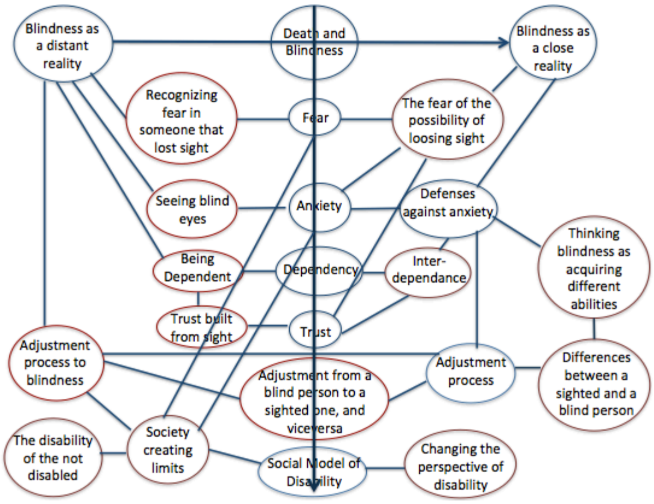


Snowflake seating- configuration (Manley, 2014).

Both the students and the researcher participated in the visual matrix. Following the Visual Matrix session, participants were asked to move to a circle to make a post-matrix discussion about the emerging themes. The visual matrix was done in Spanish, transcribed and translated to English to be analysed using thematic analysis. Additionally, two groups of experts were created, one international panel familiar with the psycho-social studies methodology and one conformed of Mexican clinicians and researchers that could maintain the analysis's cultural frame.

Results

The following map was created to map the identified themes and subthemes visually:



First, participants tried to conceptualise blindness as a distant reality, associating it with old age and their experiences of their grandparents gradually losing sight. The discussion continued with the participants focusing on the gaze they saw from people with blindness in the pictures. One of the participants described them as "without expression". The eyes of these faces, the participants said, were not focusing anywhere and appeared to be without life. These comments shifted the matrix towards the resemblance between death and blindness. "It is like dead people, but alive" was one of the associations.

The possibility of death presented an unthinkable reality to the participants: If I can die, I can lose sight. This association generated a one-minute pause, followed by the emergence of fear and anxiety. From trying to understand what someone with blindness might feel, the participants were now faced with the challenge of exploring what they would feel now that the possibility of losing sight was on the table.

Defences against anxiety were activated in the group in an immediate attempt to rationalise information. First, the group tried to understand the differences between a sighted person and a person with congenital blindness, wondering if a person with congenital blindness creates visual images when thinking in concepts as they (the participants) do. This rationalisation can be understood as a defence against the anxiety of the possibility of losing sight and maybe also as an attempt at othering a person with congenital blindness.

Next, the group started questioning the differences in the adjustment processes between a person with congenital blindness and a person with sight loss. The group was saying that a person with congenital blindness can create their world without sight but would never know what seeing is like; they will never have that visual information and reference. On the other hand, a person with sight loss could see things and hold images in their minds, making communication more accessible, but recognising the difficulty of losing the ability to see. After recognising the possibility of losing sight and the failed attempt at othering a person with congenital blindness, the group was trying to decide which condition was more challenging: congenital blindness or sight loss.

As a resource to mobilise the anxiety, the group started exploring blindness as gaining different abilities, such as improving listening skills. This comment was elicited by a young man's image with a cane (see figure 8 in appendix 9.1), suggesting the identification of the participants due to the age similarity. This identification allowed the exploration of sight loss as something that could (also) happen to young people and could represent not just a loss but the development of different abilities.

As the participants kept imagining what their experiences would be like if they lost sight, they realised they hadn't thought about the challenges people with blindness face in our society. "People with blindness cannot see the world of sighted people, but, at the same time, sighted people are equally blind to the world of people with blindness, "mentioned one of the participants.

Discussion: a first approach to the perception towards blindness in Mexico

This study explored the perception towards people with blindness by people who are not usually in contact with people with visual impairments.

First, this research showed the general belief that blindness is associated with ageing. This association is consistent with data from the WHO (2023), which states that, globally, the leading cause of blindness and visual impairments is age-related. Additionally, this study was conducted at a private university. Presumably, students and their families belong to the middle to high-income status, making preventive eye care affordable and thus minimising the risk of visual impairments. This economic possibility may explain why the first association towards blindness was related to ageing.

The recognition of the possibility of sight loss was anxiety-provoking for the participants. If we extrapolate this reaction to a broader social context, it may explain the othering people with blindness experience by sighted people. This othering may be an attempt to push that possibility as far as possible.

The study also showed a relationship between blindness and death through an association produced by one of the participants: "It is (the gaze) like dead people, but alive". This association implies that sighted people perceive an absence of reflection in the eyes of people with blindness. As mentioned in section 2.3.1, for sighted people, this sense plays a key role in the formation of identity, and it is used throughout life as a mirror that provides a visual recognition and reaffirmation of identity (Lacan, 1969; Winnicott, 1971). If this reflection is not provided, the sighted person can perceive this absence as a resistance from people with blindness to recognise them. Therefore, this association provides evidence of an unconscious resistance of sighted people to recognise people with blindness as a defensive reaction to feeling unrecognised by them. This lack of recognition translates to social barriers placed by sighted people to exclude people with blindness.

People who are not in contact with people with visual impairments are unaware of the social barriers they face. Nonetheless, the association by one of the participants who mentioned that "sighted people are equally blind to the world of people with blindness" shows the possibility for reflexivity and thus opens a possibility towards suspending the need for sighted people to be visually seen to see people with blindness.

Conclusions

This study, as part of the PhD research, represents a first approach to exploring the perceptions towards people with blindness in Mexico and, thus, understanding the social barriers created towards people with blindness and visual impairments in this country.

The results of this study are particularly relevant for this research as they provide a first approximation to unveiling the social unconscious of the Mexican population.

As mentioned in section 2.5.1, the social unconscious ideas in the Mexican culture regarding the perceptions and norms towards people with disabilities can be traced to Mexico's colonisation by Spain.

The study was conducted at a private university, where most students and their families mainly belong to middle to high-income classes and are descendants of Spanish or European immigrants (this can be traced through their last names).

In their associations, the students relate blindness to ageing by associating their experiences with their grandparents. According to the World Health Organization (2023), ageing is the primary risk factor for sight loss in high-income countries.
When they talked about their experiences with their grandparents, they seemed to think about sight loss as a typical event for people in old age. Nonetheless, their associations showed they were unaware of the possibility of sight loss for young people.

Their experiences can be related to class, as belonging to the middle to high-income class makes preventive eye care affordable and minimises the risk of visual impairments, making sight loss a natural occurrence related to ageing.

On the other hand, in Mexico, sight loss at a young age is a more common reality for people in a low-income sector because the primary health services do not cover eye care, and it is too expensive at private hospitals or clinics. Therefore, it is only affordable for some.

The perception of the students and the lack of recognition of their privileged position can reflect the dynamic between coloniser and colonised and the uneven distribution of resources (see section 2.5.1 for further reference). This uneven distribution of resources is a reality in Mexico that sheds light on the structure of the Mexican social unconscious and informs the perception towards people with blindness and visual impairments. This is further elaborated as part of the discussion of this research in section 5.2.

After conducting this study, I had a clearer idea about the differences in perceptions towards blindness and visual impairments in relation to the social classes in Mexico, which was an important input when working on the data analysis of this research.

The literature we reviewed through this chapter provided the key concepts that guided this study and were used to theorise the data obtained through this research. The following chapter presents the methodological approaches and research methods used for the present study.

3.- Methodological Approaches and Research Methods

This chapter presents the methodological approach for gathering and analysing data for this research. Section 3.1 introduces the discipline of Psycho-social studies, from which the methodology was drawn.

Section 3.2 presents the research design of the study. Section 3.2.1 sets the aim of the research and research questions. Section 3.2.2 presents my position as a researcher in relation to the research and the Mexican culture, where the study took place. Section 3.2.3 introduces the rehabilitation centres in which the research was conducted and my relation to them. Section 3.2.4 presents the planned sampling of the study, the obstacles to obtaining it, and the final list of participants of the research.

Section 3.3 presents the methods used to gather the data that was later analysed. Through section 3.3.1, I present the interview method used and my experience through the interviewing process. Section 3.3.2 mentions the public documents used as a resource to triangulate the data gathered through the interviews. Section 3.3.3 reflects on the observation phenomenon and non-verbal communication through the research, and section 3.3.4 mentions the research diary used as another source for triangulating the data.

Section 3.4 presents the methods used to analyse and triangulate the data collected from the interviews, public documents, observation and non-verbal communication, and my research diary.

Finally, section 3.5 describes the ethical considerations for this research.

3.1 Psycho-social studies

This section introduces psycho-social studies to provide background information on the methodology used for this research. This methodology was selected because it adds a psycho-social dimension to the previously conducted research on the topic by Dr. Thurston in the United Kingdom (see section 2.2). This project is the first research in psycho-social studies that explores the perception of blindness.

As a discipline, psycho-social studies explore the intersection between the individual and society. Psychological issues and subjective experiences cannot be abstracted from societal, cultural and historical contexts, nor can they be deterministically reduced to the social. Similarly, social and cultural worlds have psychological dimensions shaped by psychic processes and intersubjective relations (APS, 2023). By considering the physical condition of the body when impairment occurs and exploring the psychological and social aspects of disability, psycho-social studies can include the various dimensions of disability by studying not the person or the society but the interaction between them: the meaning *between.*

As stated by Crociani-Windland (2018), interest, as a word, comes from the etymology *inter* (between) and *esse* (to be); *Inter est* means *it is between*. According to psycho-social studies, it is in the person's interactions with the society and viceversa that the meaning lies. Accordingly, in the interaction of the researcher and participants, the meaning can emerge. According to Lacan's concept of *the third* (1960), *the truth* is never entirely said but symbolically created by the words between analyst and patient. The subject is conceptualised as the meeting point of inner and outer forces in psycho-social studies. It is simultaneously constructed and constructing, with the power to provide information and influence the researcher and the research process, and subject to power and influence by the researcher and the research (Clarke & Hoggett, 2009). As Crociani-Windland (2018) explains, *thirdness* would then be understood as the inter-subjective experience, the space between or, according to Winnicott (1971), the transitional space between the researcher and the researched.

Subjectivity is then central when doing psycho-social research, and it requires the use of reflexivity. According to Clarke and Hoggett (2009), reflexivity is the researcher's awareness of their way of thinking and inferences. Crociani-Windland (2009) adds that this process may be an opportunity for the researcher to question themselves and reassess previously constructed assumptions.

Psycho-social studies informs the development of new methodologies in social sciences that include free association, biographical interview methods and transference-countertransference dynamics (Clarke & Hoggett, 2009). The present investigation aimed to address a gap in the literature in which unconscious perceptions and associations towards blindness have not been explored. Filling this gap can help understand and address the social barriers constructed for people with blindness. This research is the first one conducted from a psycho-social perspective that explored the perception of blindness as relevant to the needs and obstacles involved in providing emotional support to people with sight loss.

3.2 Research design

This section presents the research design of the study. Subsection 3.2.1 sets the aim of the research and research questions. Subsection 3.2.2 presents my position as a researcher in relation to the research and the Mexican culture, where the study took place. Subsection 3.2.3 introduces the rehabilitation centres in which the research was conducted and my relation to them. Subsection 3.2.4 presents the planned sampling of the study, the obstacles to obtaining it, and the list of participants of the research.

3.2.1 The aim of the research

This project aimed to explore and shed light on a significant gap in the attention to the emotional support needs of people with sight loss, which, at least in Mexico, appear to be relatively invisible.

From a psycho-social perspective, this study sought to:

4. Deepen the understanding of sight loss as a process involving loss, and reconstruction, of identity,
5. Explore the needs and obstacles to implementing emotional support for acquired blindness in the rehabilitation centres in Mexico, and
6. Explore the perception of blindness and where this perception comes from.

The research questions that were designed to address those aims were:

1. What are the perceptions of blindness and the grieving process of sight loss in a rehabilitation centre for blindness, and how was this perception constructed?
2. From this perception, what emotional support services are provided by rehabilitation centres for blindness?
3. What would be the needs and obstacles for implementing emotional support in rehabilitation centres for blindness?

3.2.2 My position as a researcher

My position as a researcher was unique by having personal experiences as the principal caregiver of my mother with sight loss (see section 1.1), in receipt of "courtesy stigma" (Goffman, 1963) yet sighted, hence not quite an insider, nor an outsider. Additionally, through my professional experience, I became a psychotherapist and a counsellor for people with sight loss.

This "in-between" positioning chimes with psycho-social studies to emphasise the importance of reflexivity, allowing for measuring distance and proximity to the issues under study.

Other aspects also played a role throughout the research. First, I am a woman in a patriarchal system. The traditional gender roles in Mexico place women as caregivers of family members when they get sick or if they have an impairment. There is a social idea that women can dedicate themselves to charity because we do not need an income, as we are economically sustained by either our father or our (heterosexual) partner. I kept in mind this social perception and my emotional reaction towards the patriarchal system to maintain my position as a researcher to the best of my abilities, as opposed to challenging the patriarchal ideas that appeared through the interviews, particularly when interviewing men participants.

Additionally, my skin is white (by Mexican standards), and I have an English (Thompson) and a Spanish (Garcia) last name. I am aware my ascendents were on the coloniser's side. Furthermore, I studied for my Bachelor's and Master's degrees at a private university in Mexico and conducted my PhD studies at an English university. These privileges identify me as belonging to the middle to high-income class.
As mentioned in section 2.5.1, colonialism explains the uneven distribution of resources (Fanon, 1967). Through the research, I was aware of my position on the overall positive side of that uneven distribution.

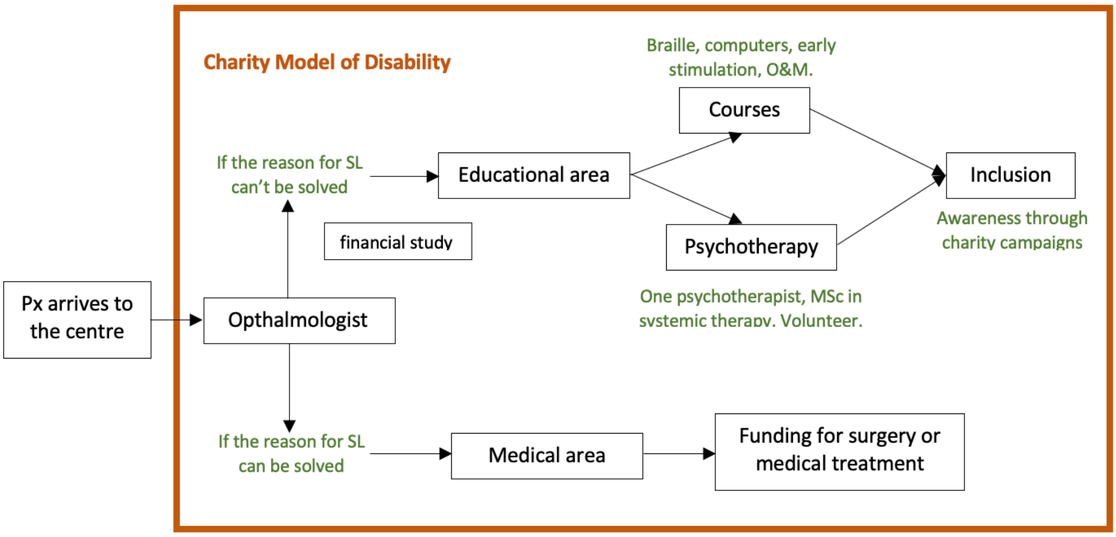
Directors and coordinators of the rehabilitation centres also had Spanish or European last names and whiter skin than some staff members and users. My last names, skin colour and international studies facilitated access to the rehabilitation centres, presumably because I "look like them" and "talk like them". Nonetheless, I was aware of the challenge this represented for some staff members and users. Unconsciously, I might be perceived as the coloniser, bringing knowledge from overseas to help them.

Throughout the research process, I kept a reflexive journal in which I recorded my emotions, thoughts, and associations. These reflections were also part of the analysed data.

3.2.3 The rehabilitation centres and my relation to them

This research was conducted in one private centre and one public centre with government funding. These centres were chosen as they were the only centres still functioning after the Covid-19 pandemic. I give here the essential details while protecting their anonymity:

1.- The **private centre** is a charity that provides services for people with blindness. The services provided by the centre are presented in the following diagram:



The patient arrives at the centre and is examined by an ophthalmologist, who determines if the condition causing sight loss is treatable.

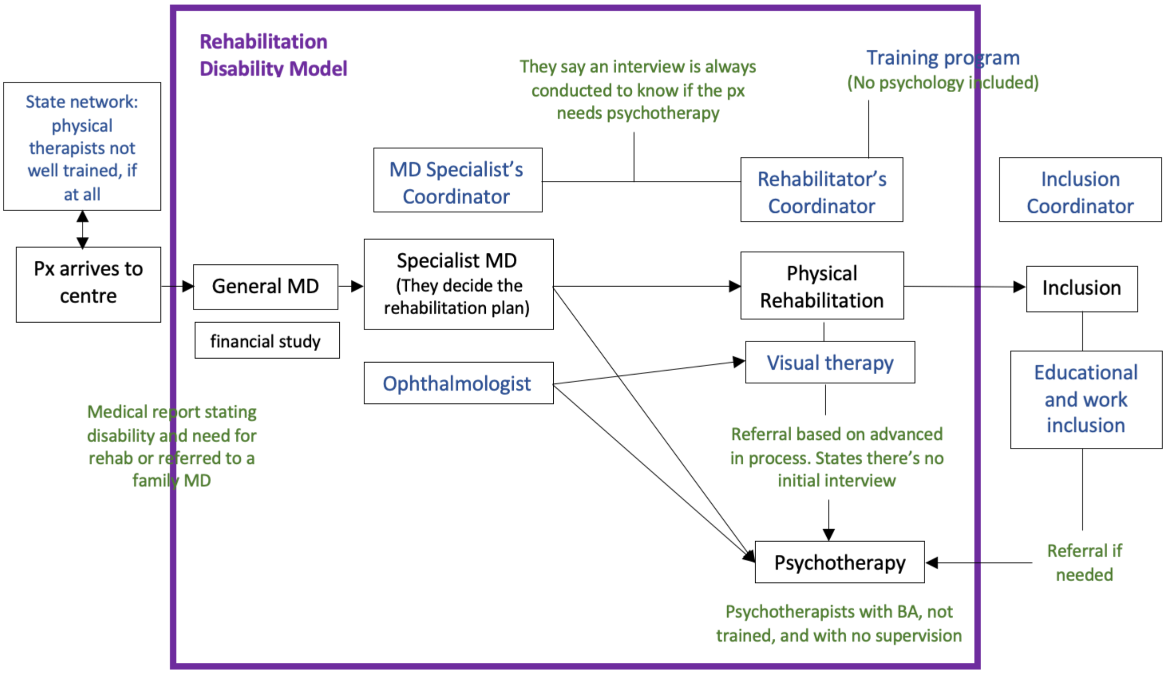
If the condition has a cure, the patient is referred to the medical area, and funding will be provided for either surgery or the appropriate treatment to avoid sight loss. If sight loss cannot be resolved, the patient is referred to the educational area.

The director of the educational area has an interview with the patient (or the family in the case of a child) to determine the relevant courses for the rehabilitation plan. These courses can include early stimulation (in the case of children), braille, computers, daily life activities, object recognition or orientation and mobility. Additionally, a financial study is conducted to determine the amount of funding to be given to the patient if they cannot afford the rehabilitation plan.

Emotional support is provided by a volunteer Psychologist specialised in Systemic Therapy. This centre does not have an official inclusion program that the patient can access after the rehabilitation plan to seek education or a job. The centre has an awareness program that includes workshops with schools and companies in which they have activities to create empathy towards people with sight loss, such as blindfolding the participants and asking them to do everyday tasks without using their sight.

My relation to this centre is particular as it was the centre that provided my mother and me with material to learn braille. I visually learned the language and then taught it to her. At the time, emotional support was not provided in the centre, and the educational area was barely starting. On the one hand, I am grateful to the centre for providing us with tools for her to learn braille. On the other hand, I feel resentful that they could not see the relevance of the emotional work-through of sight loss, which directly affected my mother. After 15 years of studying the emotional impact of sight loss, it is a priority to me to understand and try to address this gap, particularly in this centre, and to provide a space for people to work through the emotional impact of sight loss if they need or want to, so that people may not feel as my mother did going through the process of sight loss and that family members may not feel like I did. As I interviewed the participants, I considered my resentfulness and desire to address this gap.

2.- The **public centre is state funded and** offers integral rehabilitation services to people with a disability to achieve their family, social, educational, cultural, sports and work inclusion. This centre is the only official reference for people with every disability. The following diagram shows the services provided:



Upon arrival at the centre, the patient needs to provide a medical report stating the diagnosis of a disability and the referral to rehabilitation services. Otherwise, they are referred to a family Medical Doctor outside the centre. When they provide the medical report, a general MD examines the patient, confirms the diagnosis, and refers them to a specialist MD according to the disability. 12 MD specialists are working under a Medical Coordinator. One of those specialists is an Ophthalmologist.

The MD specialist decides each patient's rehabilitation plan and sends them to the physical rehabilitation area. Then, the Physical Rehabilitators' Coordinator assigns them a Physiotherapist. One of the seven Physical Rehabilitators is trained in visual rehabilitation. She follows the rehabilitation plan designed by the Ophthalmologist for all patients with low vision or sight loss.

The rehabilitation plan can include emotional support. The Psychology area comprises three psychologists who provide services to all the patients undergoing a rehabilitation process and either seek this service by themselves or are referred to it by the specialist or rehabilitator. These psychologists provide emotional support regardless of the disability.

The centre has an inclusion area that aims to contribute to the work inclusion of people with disabilities. They evaluate their skills and interests and promote a link between candidates and employers.

Before this project, I did not have any relation with this centre. My emotions towards it were negative, based on my experiences with my mother at the public medical system, where both the infrastructure and services were deficient. Upon arrival at this rehabilitation centre, I realised the government had invested resources in it. Even though gaps could be addressed, the centre has much potential in infrastructure and services.

3.2.4 Sampling as the first obstacle

The sample was aimed to be self-selecting, including two levels in each centre:

1. Professional staff:
   - One stakeholder: board member
   - One administrator: i.e. director or coordinator
   - Two rehabilitation professionals: i.e. course instructors, ophthalmologists and psychologists, if any
2. Users: two or three per centre

Access to the centres

The first centre I got access to was the charity centre. I got this access by being introduced by a friend, an ophthalmologist, to a colleague of his who is the Director of a centre for low vision. This centre provides visual rehabilitation for people with visual impairments but that still have vision. They do not work with people with sight loss that will lose their sight completely. For this reason, this centre was not considered for the research.

This low vision centre works closely with the charity. When a patient with sight loss arrives at the centre, they are referred to the charity to develop adjustment tools such as orientation and mobility or early stimulation in the case of children. On the other hand, if a patient with low vision arrives at the charity, they are referred to the centre for visual rehabilitation. Since being introduced to the Director of the low vision centre, I started collaborating at this centre, providing emotional support to patients to cope with visual impairments that represent a partial loss of sight.

The Director of this centre then introduced me to the Director of the Educational Area of the charity. After a meeting with her in which I explained the research, she helped me organise interviews with a Stakeholder, two instructors from the educational area (one of them with sight loss), the volunteer Psychologist and a user of the services who agreed to participate in the research. The Director of the Educational Area was also a participant herself.

The access to the public centre was made through the sister of one of my bosses at the rehabilitation centre for drug addiction in which the pilot study was made (see appendix 7.2). She had been recently appointed Deputy of a city district and selected to oversee the projects that aim to aid marginalised populations. Through my boss, who knew about the research, I asked her for a support letter to access the Public Centre. With that letter in hand, I asked to meet with the person in charge of research projects, and I was kindly directed to the Coordinator of Quality in Rehabilitation Services. The letter was ultimately not needed.

Through interviewing the Coordinator of Quality in the Rehabilitation Services, I understood how the centre worked. I asked to interview the (only) Visual Rehabilitator, the Ophthalmologist, a Psychologist, and two users of the centre. The three staff members agreed to participate, but since the centre is working with fewer patients now due to the covid-19 pandemic, only one user agreed to participate in the research. Additionally, she granted me access to interview the Medical Coordinator and the Rehabilitator Coordinator. Later on, I got access to interview the Coordinator of Inclusion Services.

Because the centre is governmental, the political barriers stopped me from interviewing the centre's Director. I believe interviewing the Director or the Governor himself could have shed some light on the perception of sight loss at a higher political level and the plans (if any) to improve the rehabilitation services in this centre, particularly for people with blindness.

Interestingly, I was only granted permission to interview one user in both centres. Both the centres said that the number of patients has decreased with the covid-19 pandemic, and only one decided to participate. This reason is consistent among the centres, but there is also the alternative that the patients were handpicked. With one patient per centre, I get plenty of information about that user's experience through the services, but I missed the possibility of comparing those experiences. The final sample was the following:

Charity Centre

Professional staff

- One stakeholder: board member
- One Director: creator and Director of the educational area
- Two rehabilitation professionals (teachers): visual rehabilitation courses and computers courses
- One psychologist

One user

Public centre

Professional staff

- Two directors: Director of the Quality of the Rehabilitation Services and Director of Inclusion Services
- Two administrators: Medical Coordinator and Rehabilitation Coordinator
- Two rehabilitation professionals: Ophthalmologist and a Visual Therapist
- One psychologist

One user

3.3 Research method

This section presents the methods used to gather the data that was later analysed. Through subsection 3.3.1, I present the interview method used and my experience through the interviewing process. Subesction 3.3.2 mentions the public documents used as a resource to triangulate the data gathered through the interviews. Subsection 3.3.3 reflects on the observed phenomenon and non-verbal communication through the research, and section 3.3.4 mentions the research diary used as another source for triangulating the data.

3.3.1 The interviews

The methods used in the interviewing process were the Free Association Narrative Interview "FANI" method, developed by Hollway & Jefferson (2008) with the staff members of the centres, and the Biographic- Narrative Interpretative Method "BNIM", developed by Wengraf (2001) for the users of the centre.

Staff members

The FANI method was chosen because it combines a narrative approach with the psychoanalytic principle of free association. It is particularly well suited to exploring the identification processes within a subject's life. These identifications include the sense of identity, belonging, community and affective attachments. Working at a rehabilitation centre for blindness can arouse defences against the anxiety of becoming a person with sight loss. These defences can produce mechanisms such as projective identification and exclusion. According to Hollway & Jefferson (2008), the defended subject is a central position in which a subject's defences against anxiety are mobilised when memories of events are too anxiety-provoking, making these memories likely to be forgotten or remembered in a modified, more acceptable way. These defences can affect how the information is shared with the researcher (also a potentially defended subject).

By acknowledging the co-production of meaning between researcher and respondent, the FANI method is summarised in 4 principles: using open-ended questions, eliciting a story, avoiding using "why" questions and using respondents' ordering phrasing. Using the FANI method, the co-produced understanding of adjusting to acquired blindness from the professional staff and the researcher was explored. At some moments, talking about their experience or perception of blindness was anxiety-provoking and led to a defended subject. The FANI method was also selected because its free-associative nature can provide a space for this anxiety to be contained, mobilised, and explored.

Alongside a freer narrative I had a focus on the following questions specifically related to my thesis topic:

1) What led you to work on a rehabilitation centre for sight loss?
2) Can you explain to me how does the centre work?

3) From your experience, have you encountered the need for emotional support in people with a visual impairment? If so, how do you perceive this need?
4) Are mental health services provided in the centre?
    a. If so, how are they provided?
    b. Which type of emotional support is provided?
    c. In which moment of the process is this offered?
    d. Is there a specific number of sessions?
    e. By whom is it provided?
    f. Do they/you have specific training/ experience?
    g. Is working with the family included? If so, how?
5) Do you perceive any challenges in implementing emotional support services in the centre
    a. If so, which are they?
6) Are there any regulations/protocols for mental health in rehabilitation centres for blindness?
7) From your experience, how do you think a person with sight loss perceive themselves?
8) Could you tell me more about sight loss and identity?
9) How do you think a person with sight loss is perceived by society?
10) Does the centre have any mechanism to help people with sight loss re-integrate to society?
11) Do you think emotional support could help address people's perception of themselves and their place in society? Yes /No, how?

These questions served as guideline to direct the interview and elicit free association over the research themes.

Since the first interview, I felt confident with the method as it relates to the psychoanalytic technique of free association, something I practice daily being a psychoanalyst. I had to bear in mind the need to constantly to guide the eliciting questions toward the information that the study aimed to gather and not pursue the associative chain to turn the interview into a psychoanalytic session. Additionally, as in a psychoanalytic session, I bore in mind the emotions the interview produced in me and why (as the defended subject I am). Most of these feelings were prompted by my previous experiences living through the system (and its gaps) with my mother (see section 1.1.1). Hence, when a comment was made in an interview about the improvements of the services or from a Social Model of Disability perspective, I would feel happiness and hope. On the other hand, I would feel angry and disillusioned when an ableist comment was made. I kept those emotions at bay from playing out in the interview but registered them as valuable data since, being myself a user by proxy, I wondered about the emotions these comments and perceptions might elicit in the users.

Users

The Biographic- Narrative Interpretative Method (BNIM) method, developed by Wengraf (2001), was selected for the users of the rehabilitation centres' services as it is a methodology for exploring lived experiences by facilitating the understanding of both the inner and the outer worlds. This method also explores their interactions by assuming that the narrative expresses conscious reactions and unconscious cultural, social and individual processes. BNIM is useful in psychodynamic and socio-dynamic approaches, especially in the psycho-social understanding that neither sociological nor psychological dynamics are neglected nor privileged but understood as situated through history. The methodological focus of biographic narrative-based research does not mean a collection of individual biographies but rather exploring individual experiences' in a unique historical, social and cultural way.

The Biographic- Narrative Interpretative Method was used by Peta, Wengraf and McKenzie (2018) in a study that aimed to illuminate how this interview technique facilitated the voice of marginalised disabled women. These women indicated that BNIM created a platform for those located on the margins of society, providing an opportunity to participate in the co-construction of knowledge. This method was selected because it allows for a way to explore the perception of blindness of the users of the services of the rehabilitation centres through their biographical narrative. As this is a particularly sensitive topic, the method allows the researcher not to speak directly to upsetting content should the participants wish not to. The right to withdraw also allows them to retain control over safety.

For the interviews with the users, I kept the following key notes on the BNIM principles in mind to guide me (Wengraf, 2001):

- Biography: how historical and structural aspects of society influence people's actions
- Narrative: how individuals account for themselves
- Interpretivism: acknowledge the importance of meaning

Topics to explore through life story (in no particular order):

- Reason of sight loss
- Experience of sight loss
- Experience of blindness
- Self-perception as a person with blindness
- Perception of the perception of society towards people with blindness

When conducting the interviews with the users, the tension between my personal experience, my profession as a psychotherapist and my role as a researcher was present.

I felt confident when interviewing the users through this method, as it draws from the psychoanalytic technique. Nonetheless, as with the FANI method, an obstacle I had when using this method was avoiding exploring the emotional reactions to sight loss too profoundly, turning the interview into a therapeutic session, but at the same time being aware of the interviewee's feelings and giving them a space to express them. What was helpful in that sense was keeping in mind that a researcher could explore the emotions *"but only to get to the narratives"* (Wengraf, 2008, p.6).

Another thing I had to bear in mind during the interviews was the tension between having been a user by proxy and my position as a researcher. Having been a user of the system, I could relate to the difficulties mentioned by the users. During these interviews, I struggled to focus on exploring and avoiding siding with them to address the gaps they were mentioning or challenging them to see those they were not.

Covid-19 and the pilot study: exploring the access to emotional support in the rehabilitation process for drug addiction in a residential centre

Before conducting interviews for the rehabilitation centres presented in this dissertation, I did a pilot study in a rehabilitation centre for drug addiction (appendix 9.2). This study was prompted because the rehabilitation centres for blindness stopped their operation due to the covid-19 pandemic (González, 2020). This lockdown drastically affected the course I had planned for the research. At the time, I was working as a psychotherapist in an inpatient rehabilitation centre for drug addiction. In this clinic, psychotherapy has a central role in the rehabilitation process, so the Directors decided to continue face-to-face attention by establishing safe distance measures to avoid contagion.

Assessing the COVID-19 pandemic situation with my Director of Studies and given that the rehabilitation centre for drug addiction gave the psychotherapeutic process a central role, I decided to conduct a pilot study to explore the perception of emotional support in a rehabilitation process for people with a condition that potentially compromised their identity, such as is the case with drug addiction.

Although blindness and drug addiction are two very different conditions, the similarity I noticed between them from my experience working with patients with sight loss and drug addiction is that both rehabilitation processes entail accepting a new identity.

As mentioned in section 2.2, based on Dr. Thurston's model, adjusting to sight loss requires accepting a new identity as a person with blindness. On the other hand, the Alcoholics Anonymous programme (Alcoholics Anonymous, 1981) mentions that a crucial step in recovery is accepting a problem with using drugs and a new identity as a "drug addict".

Additionally, even though from different perspectives, both conditions carry a high level of social stigma in Mexico. People with blindness are constantly perceived as unable. They face society's barriers, such as the inability to study or work, and the physical barriers to moving in a country that is not infrastructurally adapted to include people with visual impairments, such as the lack of sidewalks or hearing cues for public transportation (see section 2.4.4 for further reference). On the other hand, people with a drug addiction, despite having gone through a rehabilitation process, are commonly perceived as unreliable and face difficulties being accepted in schools and universities and finding job opportunities (Le Poulichet, 2012).

Exploring how this centre has been dealing with the difficulties faced in the rehabilitation process of a condition that compromises identity and that requires a re-insertion in society, specifically regarding the inclusion of emotional support, helped me shed light over possible challenges that could be encountered in the rehabilitation centres for blindness and provided insight for questions and themes that I had not considered for the main study.

The pilot study provided the opportunity to explore the FANI method. Even though I felt comfortable with the method itself as it is similar to my everyday work as a psychoanalyst, that same reason represented a challenge to me as, as stated before, I needed to keep in mind that it was not a psychoanalytic session and to question myself as to when to keep digging further for research purposes.

Hollway and Jefferson (2008) stated that being the researcher also entails being a defended subject in this methodology. Through the pilot study, I interviewed my bosses from the rehabilitation centre for drug addiction. I could recognise my defences against the anxiety of my bosses finding the pilot study and the questions I was asking them "smart enough" for them to believe that I am a good asset to keep employing. I was aware that the power dynamic could affect both the questions and the answers of the study. Since the main project is thought to be the starting point to address the gaps in the rehabilitation and inclusion for people with sight loss, and I have an interest in continuing my relationship with the centres, this was a crucial insight as it allowed me to be aware of the power dynamics that might come at play through the interviews.

The detailed pilot study can be found in appendix 9.2.

Conducting the interviews

The first interviews were those from the charity centre. All the interviews were conducted via video call or telephone as the centre was not open due to Covid-19 restrictions.

In biographical interviewing, the trust of participants, created by face-to-face interactions and the physical presence of both researcher and participant, is crucial. Since the covid-19 pandemic made an abrupt change towards the digital world, this creation of trust poses a challenge to the researcher of creating continuity of that presence and holding a virtual space through a screen (Moran & Caetano, 2021).

Since this was a challenge I also faced as a psychotherapist, as some of my patients decided to continue online treatment when the pandemic started, I was aware that working online was mentally and emotionally draining. The emotional distance that the screen poses makes it harder for me to *feel* the other person, and spending hours in front of a screen without leaving my house was tiring.

Nonetheless, through those virtual interactions, trust can be built differently. By both parties being home, the informal, relaxed nature of the interview can be reinforced. It places both participant and researcher in a symmetrical relationship in which they are both living through the experience of the pandemic by being confined and by exposing the privacy of their spaces in favour of the encounter (Moran & Caetano, 2021).

The interviews with one of the centre instructors that had lost sight and with the user were conducted via telephone, whilst the rest were done via video. Although visual stimuli were not needed in those participants with sight loss, physical presence is also part of creating trust. Through those phone calls, I used elements of my previous experiences with my mother and my training as a psychoanalyst and a counsellor for people with sight loss to hold those spaces through active listening (Hernández & Lesmes, 2017).

The interviews conducted in the public rehabilitation centre were face-to-face as they remained open with a reduction in the number of appointments, minimising the risk of contagion of covid-19.

At the beginning of each interview, I presented myself as a PhD researcher, explained the research, gave them informed consent (either physically or electronically) and explained that I would take notes and tape the interview (if granted consent).

I also presented myself as a Psychologist researching the grieving process of sight loss throughout my academic career. Analysing this, I believe the student position provoked anxiety in me and the thought that my research would not be taken seriously. By sharing that information about my academic career, I tried to position myself as someone with background knowledge and further questions that I was trying to answer through this research.

Following the basis of Hollway and Jefferson (2008), I created a semi-structured interview with open-ended questions. The interview opened with the question: *What led you to work at a rehabilitation centre for blindness/disability?* I aimed to open the narrative to explore the participant's perception of blindness. I followed the associations from this first question to continue exploring these perceptions. The questions were an aid for me to guide the interview to assist the narrator in talking more about their lives and associations towards blindness and avoid turning the interview into a psychoanalytic session by going beyond the research topic into a more profound personal space or by offering interpretations. As a researcher, it is hard to avoid the unconscious slip of a hypothesis or direct the interview towards where one thinks it is going. I kept in mind the unconscious slips I could register from myself, collected them in my field notes, and considered them valuable data.

I carried out six first and three-second interviews in the charity centre. The Director, Stakeholder and one of the instructors were interviewed twice. The other instructor and the psychologist did not reply to the request for a second interview. Regarding the user, they told me what they could in the first interview, and there was not much to add, so it felt enough.

The instructor that did not reply for a second interview was the one that lost his sight. This instructor plays a role in the rehabilitation centre as "the one that pushed hard enough through the barriers and made it through". He is idolised as an example for people with sight loss. In the interview, he referred to people with sight loss as "they" while excluding himself and othering people with sight loss. Through the interview, I explored the reason for his sight loss and how that led him to work at the rehabilitation centre, his role as an instructor, and his perceptions, both from his own experiences and what he lives at the centre. The remainder of belonging to a population from which he has been actively trying to exclude himself might have been anxiety-provoking and hence, a possible reason for him not wanting to accept a second interview.

The interview with the psychologist was the shortest, her replies were short and descriptive, and she cut off my attempts to deepen the topic. I felt she did not want to participate but was asked to do so. This lack of interest may be related to her position as a volunteer rather than having an official job at the centre. She did not reply to the request for a second interview.

I carried out eight first interviews and three-second interviews in the public centre. Two causes led to this choice. On the one hand, I felt the Ophthalmologist and the user had told me what they could in the first interview, and there was not much to ask or add to the information recovered. It felt enough. The Medical and Rehabilitation Coordinators and the Director of Inclusion Services were not part of the sample and did not relate entirely to the research aim and questions. The information provided was considered valuable data, but I believe further information was not required

The second follow-up interviews were more structured, created with questions that aimed to clarify or deepen a specific area, not to expand or gather more information.

3.3.2 Public documents

In a research process, using several methods to collect data is helpful to triangulate the information and contrast different positions (Hollway & Jefferson, 2013). Data from public documents from each centre was used to triangulate the data obtained from the interviews. The public documents consisted of each of the centre's web pages and flyers with basic information about the centre (mission, vision, values) and the services provided (see appendix 9.5). This data was used to understand the centres better and triangulate with the data obtained from the interviews to explore the consistency between what is said to happen in the official documents and what is happening (information from the interviews) in the dynamics in each centre.

3.3.3 Observation and nonverbal communication

In analysing narrative and biographical data information, the focus is not only on what is being said. With the researcher's use of reflexivity, how, why, and when something is being said and what feelings emerge from that data are also explored, adding an affective dimension to qualitative research (Braun & Clarke, 2022).

The research design included observing the dynamic in the centres in a psychoanalytic way based on the Tavistock method of infant observation pioneered by Bick as applied to research. This method provides insight into the subjects' lives and empirical information on the connection between what is being said in the interviews and the actions manifested in their daily activities (Datler et. al., 2014).

In the charity centre, observation was impossible because the interviews were conducted online or by phone since the centre was closed because of the covid-19 pandemic. I could not get a hold of the nonverbal dynamics at play inside the centre but had just the data from the interviews.

The interviews from the public centre were made face to face in the centre. The director of the quality of the rehabilitation services gave me a tour of the centre. My reaction towards the centre changed as I saw the state was providing resources to the centre, and they were trying to make good use of them and constantly improve the quality of the services provided. Besides the centre tour, the only other observation I was granted access to was the visual rehabilitation courses. I saw the instructor's efforts to teach the material and emotionally contain the patient.

Throughout the face-to-face or virtual interviews, I observed and made some working hypotheses about what was not being said directly but *between the lines* or entirely played out non-verbally. I wrote those hypotheses and my emotional reactions in my reflexive journal.

3.3.4 The research diary

As researchers, we cannot detach our subjective involvement. We must accept it and examine it because it helps us understand how we interpret the data. This self-scrutiny is a complex process that requires self-awareness. It is crucial as it can provide the factors that influence the researcher and, therefore, inform the dynamic between researcher and participant. This is also a complex process because the researcher and participant constantly influence each other. Nonetheless, by recognising the unconscious dynamics at play, reflexivity can also shed light over the defences against anxiety (Hollway & Jefferson, 2013).

Because of my psychoanalytic training, in which we have to be constantly aware of our feelings and separate them from those of the patient, yet keep them as data that informs either a pattern in the patient that needs to be addressed or our emotional reaction that needs to be worked through in our own psychotherapy, I did not struggle to keep my emotions and reactions in mind as the interviews were playing out. During the interview, I made practical notes to keep guiding the interview if needed. After the interview, I made notes on my emotions and reactions. I kept a journal throughout the research since I got accepted to the programme until the corrections for the final delivery.

3.4 Data analysis

This section presents the methods used to analyse and triangulate the data collected from the interviews, public documents, observation and non-verbal communication, and my research diary.

3.4.1 Thematic analysis

Once the interviews were conducted, they were transcribed. This data, along with the public document and my reflexive journal, amounted to a considerable amount of information to be analysed.

The data gathered was analysed through reflexive thematic analysis. According to Gibbs (2007), this method is one of the most common qualitative data analysis forms with the primary goal of conducting applied research. This method helps identify, analyse, organise, describe and report patterns (themes) found in the data.

Thematic analysis searches for patterns across an entire data set rather than within an item. It is not based on any theoretical framework. Therefore it can be used with many. It can be essentialist (reporting experiences, meanings and reality), constructionist (examining the way experiences, meanings, and reality are the effect of societal discourses) or contextualist (recognising how individuals make meaning of their experiences and how social context influences those meanings) (Braun & Clarke, 2006). Considering that the research aimed to explore the perception of sight loss and access to emotional support in rehabilitation centres for blindness, the theoretical framework used in the thematic analysis was contextualist.

As Braun & Clarke (2006) mentions, a theme captures something important concerning the research question, and it represents a pattern across the data set. Themes are not selected necessarily because they appear a determined number of times in the data but because of what they capture from the data in relation to the research questions. Therefore, the researcher's judgment is crucial in selecting a theme.

For this analysis, themes were selected using a theoretical approach. This form of thematic analysis is driven by the researcher's theoretical or analytic interests. Nonetheless, when analysing the data gathered, it is not uncommon to "discover" new, emerging themes that were not initially considered or tackled through the research questions. Ely et al. (1997) mention that those themes are not in the data but in the researcher's mind that creates connections as they think about it.

The data was analysed using latent thematic analysis, which goes beyond the presentation of data to identify the underlying assumptions, conceptualisations, and ideologies. It seeks to interpret and theorise the meaning of the patterns and their implications (Braun & Clarke, 2006).

In working through the thematic analysis, I considered using the *NVivo* system to analyse the data. I even attended a seminar to learn how to use the platform. Nonetheless, it seemed artificial and took the affect out of the analytic process. I chose to accept the challenge of having the internal capacity to hold the data in my mind (Hollway & Jefferson, 2013). A challenge for me was to think about the rehabilitation centres together in a cross-sectional way. I could think about each centre at a time, but it was challenging to think across them from the emerging themes. This difficulty, and the anxiety that accompanied it, expressed itself in the first delivery of the findings. In this delivery, I presented all the data from the interviews and the public records, even if they were irrelevant to the research, and excluded my reflections almost completely. "A failure to analyse" (Braun & Clarke, 2006, p.25). After revising the document with my supervisors, I worked through the findings again, re-reading the interviews to re-identify emerging themes, and triangulating this information with the one obtained from public records, my reflexive journal and the data panels that were conducted to find and analyse the emerging themes cross-sectionally between the centres.

3.4.2 Triangulation

One way of triangulation through the study was to compare what was being said in the interviews with the official documents from the centres to grasp the gaps in the services provided by the centre and the ideology from which it operates.

Reflexive approaches emphasize subjectivity in coding and analysis (Braun & Clarke, 2022). As the researcher is subjectively involved in the research and co-constructing the meaning with the participant, it is crucial to corroborate whether the results they see in their analysis are also seen by others (Kroger, 2021).

Keeping this premise in mind, I was aware that my personal experience with my mother and my training as a psychotherapist could unconsciously guide the data analysis.

Two panels were conducted to triangulate the data. One of the panels was conformed by colleagues from the psycho-social studies programme from the University of the West of England. This panel was particularly helpful in triangulating on my experience with the methodology. The second panel was conformed by Mexican researchers and psychologists that could triangulate within the cultural context.

3.5 Ethical considerations

This research has gone through a full ethics review and has received clearance from the University of the West of England (see appendix 9.3).

All participants were at least 18 years old. Informed consent was gathered from all participants. Staff members were asked to sign the written consent form (see appendix 9.4.1 and 9.4.2). Users of the services of the rehabilitation centre for blindness were asked for verbal consent through the reading of the consent form by the researcher. The verbal agreement of the participants was audio-recorded (see appendix 9.4.3 and 9.4.4). Providing the information in braille was not possible due to limited resources and the difficulty and high cost of printing material in braille in Mexico.

The interviews were audio-recorded, and all the information was anonymized and stored in a secure, password-protected folder on UWE One Drive, accessible solely to the researcher, the Director of Studies and the supervisor. Transferring identifiable data was not needed.

The sensitive aspect of the information being asked was also taken into consideration. Because of my training as a psychotherapist, I was able to provide containment when needed.

I am currently a licensed psychotherapist with a private practice. I attend psychoanalytic psychotherapy twice a week and have a supervisor for my clinical work. My Director of Studies and supervisor are constantly reviewing my work. I am also a part of the Psycho-Social Learning community at UWE and have formed a group of colleagues in Mexico. Both groups provided peer support and a place to triangulate data to avoid wild analysis. These actions provided support in every step taken during this research to ensure no harm was caused to the participants.

4.- Findings

4.1 Introduction

This project was prompted by my experience as the daughter of a mother with sight loss (chapter 1.1). When she lost her sight, a charity provided us with tools to learn braille. Nonetheless, neither the centre nor the health care professionals offered emotional support, nor did my mother or family seek it.

As mentioned in section 1.2, my first attempt to implement emotional support at the charity that had previously helped my mother and I faced the social barrier of the administration of the charity saying emotional support was not needed for someone to adjust to sight loss. After facing this barrier, I designed this research to deepen the understanding of sight loss as a process involving loss, and reconstruction, of identity, and to explore the perception of blindness and emotional support in rehabilitation centres to understand the needs and obstacles to implementing emotional support for people with sight loss.

This study was conducted in two centres (section 3.2.3). One of the centres treats only people with blindness and visual impairment. It was the one that aided my mother and me. At the time, psychological attention was not provided. When I started this research, the only information I had was that they provided emotional support by volunteers who may or may not be psychologists and they had previously told me that emotional support was not needed for someone to adjust to sight loss (chapter 1.2). The second centre provides rehabilitation services for people with all impairments (not only visual). I knew nothing about the psychological services offered, if any. This chapter presents the findings.

The chapter is divided into five parts. Section 4.2 explores the resistance to incorporating emotional support for people with sight loss through understanding the perception of sight loss in rehabilitation centres. Subsection 4.2.1 presents the foundation of the centres as the baseline of the perception towards people with blindness. Subsection 4.2.2 presents the visible and the invisible to secure funding. Subsection 4.2.3 presents the perceptions towards people with blindness. Subsection

4.2.4 presents the self-perception of people with sight loss. Subsection 4.2.5 presents the perception towards the grieving process of sight loss.

Section 4.3 presents the current emotional support services and the needs and obstacles of these services in the rehabilitation centres. Subsection 4.3.1 presents the perception of the relevance of emotional support as part of the rehabilitation process. Subsection 4.3.2 presents the resources (and lack thereof) in the psychology area. Subsection 4.3.3 presents the gaps between what is being said and done regarding emotional support. Subsection 4.3.4 present the challenges of working with families. Subsection 4.3.5 presents the perception and resistance of the users of emotional support services.

The research questions seemed to offer the opportunity for reflection on the centres' beliefs regarding their emotional support services. After one of the interviews, the charity that aided my mother decided to hire a psychologist and asked for my help as a consultant to train them and help develop the psychology area inside the centre. Section 4.4 presents my process of becoming an academic activist and how that has deepened and shaped this research.

Once I had the opportunity to contribute to promoting the creation of the psychology area of both centres, the next question came to my mind: "Adjust to where?" Even if a person with sight loss is fully adjusted emotionally to blindness and has the tools needed to live their everyday life, inclusion is limited for people with impairments in Mexico. Following this question, I took one further step in this research and interviewed the Director of Inclusion Services in the public centre. This is the only centre that provides these services for people with disabilities (not only blindness). Section 4.5 explores the inclusion services the centre offers and the obstacles they have faced. Subsection 4.5.1 presents the perception (projection) from society towards people with disabilities. Subsection 4.5.2 presents the recognition of the social barriers but the ignorance of the social model of disability. Subsection 4.5.3 presents the inclusion services currently provided. Subsection 4.5.4 presents the hidden purpose within "inclusive" companies. Subsection 4.5.5 presents working conscious and unconscious perceptions within the inclusion area in relation to working at factories as the only option for people with disabilities. Subsection 4.5.6 presents the the educational gap and the need for inclusion at all educational levels. Subsection 4.5.7 presents the importance of awareness and the workshops provided by the centres.

The information presented in this chapter is the result of the thematic analysis and triangulation from the data obtained through the interviews, as well as information gathered through public documents that detailed the center's services, observation and non-verbal communication, and my reflexive diary.

4.1.1 Introducing the participants

The charity centre

Carlos (pseudonyms are used throughout) is a board member of the charity. He has over 40 years of experience running charities and as a stakeholder in the city's archdiocese. Another board member invited him to be part of the charity's council 20 years ago. *"I try to help as much as possible. I participate in every charity in which I represent the church. This charity does great work, and I feel affection towards it. God has granted us life and health, and we must help. Someday we will be asked to take accountability for what we did. Also, I need to be an example for my kids and grandkids, that is very important because they are married and do not have any problems, but they will be ungrateful not to help those in need."*

Ruby is the Director of the Educational Area of the charity, where the rehabilitation courses take place. She had a previous job as an inspector of special education, but she felt it was too administrative and stopped having meaning for her. She was invited by a doctor who was working as a volunteer at the charity and with whom she had worked previously to create the early stimulation area of the centre. She started working as a volunteer in the afternoons to consolidate the area. *"They were basically a medical centre, but the ladies that founded the charity had the idea of continuing to see the development of the children who got surgeries to improve their sight. That is where the idea came from."* What started as the early stimulation area is now the educational area, which includes early stimulation, rehabilitation courses for children and adults and (now) emotional support. Then life took her to another city, from where she continues directing the area by distance up to this day.

Andrea is a Visual Rehabilitator of the charity. She started working there as a student 12 years ago and got a job offer when she graduated. *"I really like the art of teaching and finding different ways. If a child cannot do something in a certain way, there is another one. I mean, seeing the different ways of teaching a child."*

Rolando is the computer instructor of the charity. He lost his sight when he was 14 years old. The diagnosis that led to his sight loss was never clear. After feeling sad for a month and a half, he decided he needed to do something to figure out how to continue his life. With his parents' support, he requested the school for the opportunity to continue studying. He asked a classmate to read to him, and he would memorize the reading and do the work he needed. He then pursued a degree in computing. Rolando started attending the charity as a student to learn braille. After he completed his course, he was offered a job as a computer instructor, which he has held for seven years. *"I was here (at the charity) for a short time before they offered me the chance of working as part of the instructor's team because I had the experience and knowledge in computers."*

Patricia is the Psychologist at the charity. She has an M.Sc. in Systemic therapy. She was invited by the Director of the centre (her friend) to work as a volunteer five years ago. *"That is how I arrived here. The truth is…it was a direct invitation from her (the Director of the charity), and well, I accepted."*

Daniela is a user of the charity services who lost her sight when she was 14 years old due to a brain tumour. Two years after losing sight, her mother heard about the charity and made an appointment. *"At first, I did not want to go to the centre because I believed it was useless, as I was already blind. So I just cried even more. I felt very sad and angry all the time. But then I found out there were resources and things I could do. I have learned a lot, and I have found hope."*

The public centre

Marycarmen has been the Director of Quality of Rehabilitation Services in the public centre for five years. She's in charge of improving the quality of rehabilitation services from the moment a patient arrives at the centre until they get their treatment. *"I was surprised when I started working here because you think about a disability as something distant, very distant. If you do not have anyone in your family with a disability, you see it as something far away from you, like it is not going to happen. However, now that you are here, you realize that at any moment, any person, including us, can acquire a disability. Knowing the services available has been very gratifying because it helped me realize my problems are not that big, so it encouraged me to ask myself how we can help the population so that their condition is not an impairment."*

Miguel is the Coordinator of Medical Services. He coordinates the medical doctors that provide the initial consultation, diagnosis and rehabilitation plan." I am *the coordinator of all doctors. We are like 20. We have rehabilitation doctors, one paediatrician, a neurologist, an ophthalmologist and an otorhinolaryngologist. Depending on the disability, they get referred to the different specialities we have."*

David is the only ophthalmologist working at the rehabilitation centre. He was looking to work for an institution, and the centre had an opportunity. *"Before starting to work here, I thought that because it depended on the government, it was going to be deficient, but it is very well-equipped, and the work environment is very good. You try for the patient to have the best option, and well, this is it. The truth is, here you can do a little bit of help, even if just a little."*

Alex is the Coordinator of Rehabilitation Services. He coordinates the staff that provide rehabilitation services for people with all disabilities. *"The rehabilitation area is focused on people with a disability, either visual, hearing, etc. However, we are more focused on the motor disabilities."*

Ana is the only visual rehabilitator working at the public centre. She is a physical rehabilitator that was working at the centre and was asked if she could take on the visual rehabilitation position. *"I knew nothing. I knew about braille, the Perkins machine, and the cane, but nothing in depth. Nevertheless, now I have been here three years, and I see it differently. I did not know how much they struggled to adapt to life and the city because the city is missing so many things to facilitate their everyday life activities. Now I introduce myself in how they live, how their social life develops… some things like those, more intimate, more in-depth."*

Mariana is the leader of the psychology team. She studied physical therapy and worked as a physical therapist at the centre. Then she studied Psychology as her second bachelor's degree. *"I noticed the patients were telling me their problems at the physical rehabilitation sessions. I wanted to do more than just listen. I wanted to be able to help them. So I pursued a psychology degree and asked to be relocated to the psychology area."*

Claudia is the user of services at the public centre. She is the mother of Juan, a nine-year-old boy diagnosed with cerebral palsy at nine months. He has been taking physical rehabilitation at the centre since his diagnosis. Six months ago, they were told he was gradually losing sight, so he started taking visual rehabilitation as part of his treatment plan. *"The doctor told me he has going to be like a plant, that he would not be able to do anything, but that is why I have him in rehabilitation, so he could do the most he can. The truth is that the centre supports people with disabilities. They have cared for my child. I feel the system is good, and the therapists are excellent."*

Alexa is the Director of Inclusion services at the public centre. She was hired two months ago and is currently learning how the area works and finding ways to improve the services. *"I want to leave my mark, to do something with meaning that helps other people."*

After introducing the participants, the following section starts presenting the results.

4.1.2 The emerging themes

The following table provides an overview of the themes that emerged through the data analysis:

Theme	Subtheme	Sub subtheme
	Foundation of the centres and its impact in the current perception of blindness	The charity model of disability: helping as the expiation of sins.
		The rehabilitation model of disability: the relevance of showing results
	The visible and the invisible to secure funding	"I've only seen happy faces", says the charity benefactor
		"Sight loss isn't profitable, it's a permanent condition that doesn't show improvement, the government won't invest in

Why is there a resistance to incorporate emotional support services for people with sight loss? Understanding the perception of sight loss inside the rehabilitation centres.		it", says the medical coordinator
	Perceptions towards people with blindness in the rehabilitation centres	Helping: reason for working at a rehabilitation centre and the change of perspective towards people with blindness
		"We have to help the less fortunate", feelings of pity towards people with blindness
		"They're very brave", recognition of resilience in people with blindness
		Bread and circus to the people: wanting the benefits for the impairment without working through their rehabilitation
		Different from "us": othering as a defence against anxiety
	Self-perception of the users as people with sight loss: similarities and differences between how they see themselves and how they're being seen by staff members	
	The grieving process of sight loss: a dynamic process	Perception of the grieving process of sight loss from staff members
		Experiences from the users
		Sight loss and identity: a personal definition
	Perceptions of the relevance of emotional support as part of the rehabilitation process	
	Resources (and lack thereof) within the centres:	

Where are we? Current services, needs, and obstacles for the implementation of emotional support in the rehabilitation centres for blindness	psychologist’s training as a crucial gap	
	Gaps between what’s said and done in the access to emotional support: centre’s response to emotional reactions from the users	
	Support vs overprotection: working with families	
	“I’m not crazy”: perception of the users and resistance to access emotional support services	
Becoming an academic activist during this research: bridging the gap for including emotional support at the rehabilitation centres for blindness		
What’s next? Inclusion services and their obstacles	Not seeing and not wanting to see: perceived perception (projection) from society towards people with blindness within the rehabilitation centres for blindness	
	Pushing hard enough to get through the barriers: the ignorance of the social model of disability	
	Inclusion services provided	
	Saving money and reduced taxes: the hidden goal within “inclusive” companies	
	The conscious and unconscious perception within the centre regarding work inclusion. Working at	

	factories: the only option to get “a little money”	
	Educational gap: the need of inclusion and awareness at all educational levels	
	The importance of awareness: workshops provided by the centres	

4.2. Why is there a resistance to incorporate emotional support for people with sight loss? Understanding the perception of sight loss inside the rehabilitation centres.

Through this section, I present the emerging themes and subthemes that shed light on the perception of staff members and users of the rehabilitation centres to understand the resistance to incorporating emotional support for people with sight loss as part of the rehabilitation scheme.

Subsection 4.2.1 starts by presenting the reason for the foundation of the centres and the perception with which they were created to explore how this original idea might influence today's perception.

Subsection 4.2.2 presents the visible and invisible of the rehabilitation centres used to secure funding and how that way of handling information impacts the perception of the relevance of emotional support as part of the rehabilitation process.

Section 4.2.3 presents the perceptions toward people with blindness found within the rehabilitation centres to understand the way people with blindness are being seen, the position in which they are located, and how these perceptions might inform the barriers to the implementation of emotional support as part of the rehabilitation process.

Section 4.2.4 presents the users' self-perception as people with sight loss and the similarities and differences between how they see themselves and how the staff members see them.

Finally, section 4.2.5 presents the perception of the grieving process of sight loss from the staff, the experiences of the users, and the reflections on the relationship between sight loss and identity. This section aims to understand if these perceptions influence the access (or lack of) emotional support within a rehabilitation plan.

4.2.1 Foundation of the centres and its impact in the current perception of blindness

The first thing I decided to look at was why the centres were created. Since their foundation, the centres have established the way of doing their work, and it was interesting for me to explore how that founding perception informs the way the centres work now. Because the foundation bases are unique, this section is divided by centres.

4.2.1.1 The charity model of disability: helping as the expiation of sins

The charity centre was created in 1997 by a group of friends who realised there was a high demand for eye surgeries and medical treatment to avoid sight loss. They decided to build an association where people with visual impairments who could not afford the necessary treatment could get funding (Destellos de Luz, 2022).

This group of friends comprised only women, daughters and/or wives of wealthy men. It is not uncommon in Mexico, where the macho culture predominates, that women born or married into money do not work themselves but allocate resources to create charities or projects to "help the less fortunate".

Those patients who could not avoid sight loss or recover sight by medical intervention were turned down, but there was nowhere to refer them for rehabilitation. According to the webpage, this group of friends (who called themselves "the women of the patronage") had a hard time letting go of the children who could not avoid sight loss with medical treatment. Therefore, they created an educational area to provide courses to help people with sight loss adjust to blindness.

Although the result of creating the educational area led to people having resources to adjust to sight loss, the fact that this area was created because the women of the patronage wanted to follow up on the children who could not avoid sight loss could also be seen as a reflection of the culture of motherhood in Mexico, where mothers struggle to let go of their children to let them grow up. This is further explored in subsection 4.3.4.

The centre follows a Catholic ideology and promotes the discourse of the Charity Model of Disability. This model sees people with disabilities (or other minorities) as incapable (Masters, 2022). Therefore, those who help them are "privileged" and use that privilege mercifully, helping those in need. The centre has the image of Jesus of mercy in the waiting room:

Divine Mercy, by Adolfo Hyla (1943)

This image may aim to send the message from the centre that God will have mercy on them, or it might reflect the positioning of the centre founders and staff as merciful saviours helping those in need.

This ideology also manifested in the interview with Carlos. He mentioned, *"Seeing is a privilege. God granted us health. We have to help those who were less fortunate"*. Carlos believes he is earning heaven with his aid to the charity. As he mentioned in the interview, *"Someday we will be judged, and we will have to be accountable for our actions. I try to help as much as possible."*

At the beginning of the interview, I explained that I am a psychologist who works with people with sight loss. During the interview, he tried to convince me to work as a volunteer in the centre, using arguments such as *"we need to pay forward what was given to us", "this would be an exceptional opportunity for you"*, and "*it would be vulgar to help while looking for financial benefits".* I interpreted this attempt as if he wanted me to feel guilty for having an able-body, so I would accept taking a position as a volunteer instead of the centre hiring a psychologist that provides emotional support. This attempt shed light on the possible way in which people are hired to work at the centre, possibly underpaid, if paid at all, and with the ideology that they are fortunate and should help those in need. It also explains why the psychologist works at the centre as a volunteer.

Since the foundation of the centre, patients have been seen as "less privileged", "in need of help", and "poor", while those who help them are placed as "merciful" and "securing a place in heaven." The centre, being a charity, tries to expand that view to society and generate pity for people to donate. This dynamic, along with the influence of the charity model of disability, may influence the way people with blindness are perceived by society.

4.2.1.2 The rehabilitation model of disability: the relevance of showing results

The public centre is a governmental facility. It gets its resources from the government. In Mexico, there is no strategic planning for the country's development. Every person who wants to take on a governmental position creates a campaign in which they promote specific projects that aim to support the country in one way or another. These projects are usually based on their personal interests. When taking on that position, which lasts for six years, the promised project(s) take place, and there must be tangible results. There are several problems with this. In the first place, the started project is not followed-up beyond that period, so every effort made is lost after six years. If the next person in that position is interested in the same topic and supports an initiative, it is usually with a new project, so the progress will most likely be lost. If the interests are not aligned, the progress in that area is halted until the next interested person is in power.

Because there must be results shown at the end of that period, resources are provided to those projects that can produce results in the shortest time. In terms of working with people with disabilities, such as this rehabilitation centre, resources are not given to rehabilitation for people with sight loss but rather to people with disabilities that can heal with physical therapy and whose improvement is visible.

Miguel mentioned: *"You can see when a person who could not walk walks again, or a person with an injury in their arm recovers movement, but someone with sight loss will not see again, there is no improvement to show."*

The idea that rehabilitation only includes recovering what was damaged and excludes the adjustment process to a permanent condition reflects the Medical Model of Disability, in which disability is seen as something "wrong" that needs to be fixed (Dirth & Branscombe, 2017). The need to show results from the centre in terms of rehabilitation (and excluding adjustment) can shed light on the lack of resources for people with sight loss or visual impairment. This lack of resources extends to training, as there is a lack of formal training for physical rehabilitators in the visual area. *"If a physical rehabilitator wants to work with people with blindness and visual impairments, they have to get that training elsewhere. You do not get it through the degree,"* explained Alex. This is also the situation for psychologists working with people with sight loss and visual impairments. If we want to learn how to work with these patients, we need to get training elsewhere, potentially outside the country.

4.2.2 The visible and the invisible to secure funding

This section explores the seen and the unseen inside the rehabilitation centres to secure funding and how this process directly affects the incorporation of emotional support as part of the rehabilitation plan. As with section 4.2.1, each centre's dynamic of the seen and the unseen is unique. Therefore, this section is also divided by centres. Subsection 4.2.2.1 explores these processes in the charity centre and subsection 4.2.2.2. in the public centre.

4.2.2.1 "I've only seen happy faces", says the charity benefactor

Carlos mentioned that he had *"only seen happy faces, never angry or sad faces".* This statement felt as if he was either utterly oblivious or negating reality and seeing what he wanted to see.

Later, Ruby told me they had to *"show the benefactors the success cases so they would keep investing."* This made sense of the perception of the member of the council. He was not oblivious but unaware of the actual situation.

It appears that the rehabilitation centre believes that if they show the benefactors people going through the grieving process, they will not provide funding. The fear or assumption seems to be that the painful emotional reactions in the grieving process are perceived as a sign of failure of the centre's services.

This set of assumptions from the centre's staff about how to procure support shed light on the message I received four years ago: psychotherapy is unnecessary for a person to adjust to sight loss (section 1.1.2). Of course, by presenting only happy faces to the council, they enhance the idea that access to emotional support is not needed.

Along with the Charity Model of Disability practised by the centre, the misconception of the council that there are only happy faces in the centre adds to why a psychologist was working as a volunteer rather than adequately hired. According to Andrea, the criteria to send the patients to the psychologist are that *"they seem sad or struggling with the grieving process, or they are not advancing in the courses as they should be."* Reflecting upon this interview in one of the data panels, one of the participants mentions that it is almost as if when identifying a sad face, they must send them to the psychologist to make the face happy again, dismissing the relevance of working through the emotions of sight loss.

4.2.2.2 "Sight loss isn't profitable, it's a permanent condition that doesn't show improvement, the government won't invest in it", says the medical coordinator

As mentioned in section 4.2.1.2, the need to show results from the public centre in terms of rehabilitation (and excluding adjustment) can shed light on the lack of resources for people with sight loss or visual impairment.

Regarding this lack of resources, Miguel mentioned that *"there is no training to work with people with sight loss because it is not profitable. There are not enough people with sight loss to make the career profitable. Vocation is required to work with this population because it is not profitable. If you are a woman, your husband is maintaining you, and you can work because you want to, you can dedicate to this, but if you are a man that has to support a family, you think about it twice."*

This comment evidences, on the one hand, the lack of recognition of the emotional support needs of people with sight loss. On the other, stating that a woman could dedicate to this as her husband supports her. However, a man supporting a family would have to think about this twice gives a brief but powerful illustration of the enduring patriarchal structure of Mexican society.

This comment produced anger in me. I decided not to pursue a confrontation regarding the patriarchal system, as this was not the purpose of the interview or the study, and it could lead to Miguel feeling questioned or attacked and for him to close off in the following questions. Nonetheless, I did question his idea regarding the lack of enough people with visual impairments to make training in visual rehabilitation profitable. I mentioned that almost 30% of the Mexican population has blindness or visual impairment. He was surprised by this number and then concluded that *"sight loss is not profitable because it is a permanent condition and it does not show improvement."* Therefore, resources are allocated to physical rehabilitation so the government can use those numbers to show their results.

The perception that sight loss is not profitable because it is not a rehabilitative condition sheds light over the core perception within the centre of blindness of it being a death sentence. Additionally, the fact that he was surprised by the data shows that they do not receive many people with blindness or visual impairments. The perception mentioned by the rehabilitation coordinator is that "*the referral to receive rehabilitation for people with blindness and visual impairment is the charity."* The charity, however, only receives a few patients, certainly not 30% of the population. This data infers that many people with sight loss are not reaching rehabilitation services, evidencing an apparent problem of disconnection between the medical sector and the rehabilitation services in which people diagnosed with a condition that will lead to sight loss are not being referred to the rehabilitation centres.

4.2.3 Perceptions towards people with blindness in the rehabilitation centres

This section presents the subthemes that arose from the interviews that shed light on the perceptions toward people with blindness. Subsection 4.2.3.1 explores why the staff members work at a rehabilitation centre and how that reason affects the way they see and act towards people with blindness. Subsection 4.2.3.2 presents evidence of a perception of people with blindness as evoking feelings of pity. Subsection 4.2.3.3 informs on the recognition of resilience that the staff members perceive in people with blindness. Subsection 4.2.3.4 mentions the cultural barriers whereby a person with blindness or sight loss goes to the centre not to rehabilitate but to get a card that gives them discounts. Subsection 4.2.3.5 presents the perception mentioned by the staff members of people with blindness being “different from us”, as a defensive reaction to the possibility of losing sight.

4.2.3.1 Helping: reason for working at a rehabilitation centre and the change of perspective towards people with blindness

Even though coming from different positions, most interviewees share the reason for working in a rehabilitation centre: to help.

As mentioned in section 4.2.1.2, Carlos mentioned supporting the rehabilitation centre to *"help the less fortunate".* Alexa mentioned that she started working at the centre after several years in the private sector because she wanted to contribute to society and *"leave her mark".* This ideal relates to Ruby’s reason for working at the rehabilitation centre , as she mentioned finding meaning working there, something she could not find at her previous job in the educational field: *"They* (her bosses) *were asking me to treat the children as if they were pieces of papers* (referring to the administrative tasks), *I could not find meaning working there."*

Andrea and Ana mentioned they wanted to work at a rehabilitation centre to help. Ana mentioned, *"When I was a little girl, I saw these programs where they talk about people with disabilities and how they helped them, and I knew I wanted to grow up and help them."*

Miguel and Alex mentioned that *"vocation is needed to work with this kind of population."* This comment is related to their view that working with sight loss is not profitable. However, they also mentioned that people working with people with disabilities *"have to be able to stand seeing difficult things, knowing it could happen to them".* Alex mentioned that the university tested for vocation when he was studying, and many students were turned down if they did not have it. Although there is a hint of pride in their discourse for being able to face seeing disability, knowing it could happen to them, this perception can shed light on a possible reason for the rejection of society in general towards people with disabilities, including blindness.

Some participants mentioned changing their perception of people with blindness when they started working at a rehabilitation centre. Alexa mentioned, *"Before, I used to think about them with pity, but now I know how to help them, and I feel more admiration than sadness."*

Helping plays an essential role in the reason for working at the rehabilitation centre. Nonetheless, as seen in sections 4.2.1 and 4.2.2, the reason for helping shapes the way of providing that help. The following sections explore those reasons for helping to present a clearer picture of the perception of people with blindness in rehabilitation centres.

4.2.3.2 “We have to help the less fortunate”, feelings of pity towards people with blindness

Pity was one of the most common emotional reactions, and it was represented in different ways.

As mentioned in section 4.1.1, one of the expressions of pity was represented by Carlos through the need to *"help the less fortunate".* He gave an example of this "pity-driven help" by mentioning that some children sell candy across the street from his office, and he sends his assistant to buy the candy. *"We have to buy the candy they made. They have been on the street selling them all day. It is their work. We have to help them."* I found this comment striking and had a hard time writing about it. The fact that Carlos appears either oblivious or not caring about children missing school and selling candies in the street and believes that buying candy from children with blindness who sell them on the street is the way to help them is shocking. His view clearly comes from the perspective of the Charity Model of Disability. What I found hardest to swallow was the pretence, either conscious or unconscious, of not giving charity by "admiring their job selling candies". This example also illustrates the lack of access to formal education and proper jobs for people with blindness. Miguel mentioned, *"it is good that they can get their 'little job' to earn their 'little money' and feel productive."* As if referring to children that were playing to work but weren't productive, as opposed to children not having access to school and having to sell candy in the street.

Pity was also hiddenly manifested in the surprise shown by the interviewees at what people with blindness can achieve, such as Marycarmen mentioning: *"...now I know how to help them, and I feel more admiration than sadness."* Alexa also expressed this in phrases such as *"the way they make a sandwich, wow"*, *"they come and go, wow", and "it is impressive how they move from one point to another, and they manage to arrive, it surprises me, and I like it."* This reaction of surprise entails that they had not thought people with blindness were capable of doing the things they mentioned, like making a sandwich or moving from one place to another. Otherwise, the ability to perform said activities would not come as a surprise. It was interesting how, when asked directly about their perception towards people with blindness, feelings of pity are not mentioned directly but hiddenly evoked in phrases such as *"less* *fortunate"* or *"surprisingly capable"*. Alexa struggled with her answer, mentioning, *"I have never seen them with pity, not with pity, more like 'poor them"*.

Nonetheless, when asked about the perception they believed society has towards people with blindness, most interviewees mentioned pity, compassion, and uselessness. Perhaps the distance of talking about society's perception made it easier to talk about their perception projected towards the eyes of society. This is further explored in section 4.5.5.

4.3.3.3 "They're very brave", recognition of resilience in people with blindness

Another perception was the recognition of resilience. Some interviewees mentioned perceiving people with blindness as *"very resilient", "very brave"*, and *"trying very hard"*.

They also mentioned the perception of fighting through the barriers as resilient characteristics., such as *"moving in a city that is not adapted"*, as mentioned by Alexa or *"achieving making a life with an impairment,"* expressed by Ruby. *"They are courageous. Not all of us could do it,"* mentioned Miguel.

Although the idea of resilience is to bend but not break when going through a difficult situation, the expectation that people cannot and those who can are superhuman and should be admired is ableist. It allows the able-bodied to pity while doing nothing to remove barriers or secure that other physical or psychological resources to support those less than superhuman to adjust to society are available. People with blindness did not choose to be born without sight or lose it along the way. They had to go through it. What could be admired is the strength to walk the path, but not the fact of having to face it. Moving in a city that isn't adapted, for example, should not be seen as a resilient adjustment to blindness, but as a failure of society to be inclusive. Feeling admiration for being able to adjust, regardless of the barriers, should help to recognise and break them. The problem seems to be the focus on the individual and the expectation that it is up to them to adjust. There is no room between the superhuman and the pitiable ‘poor them’. Social barriers are further explored in section 4.5.

4.2.3.4 Bread and circus to the people: wanting the benefits for the impairment without working through a rehabilitation process

In Mexico, a common phrase often goes "*al pueblo, pan y circo"* (bread and circus to the people). This phrase is a translation from *panem et circenses,* from the Sátira X written in 100 A.D. by Juvenal in Rome. In the play, the sentence refers to Julius Caesar distributing wheat for free and providing circus representations and entertainment to gain political power. The underlying meaning of the phrase is that if you give people food and entertainment, they will never revolt. I believe this phrase defines the social situation in Mexico. An observation I’ve noticed as a cultural participant in this country is that education is intentionally limited to secure control of the population. Additionally, during political campaigns, politicians buy votes from people by giving them food in exchange for their voting credentials. This enhances the cultural belief that free things are better than earned things and the law of minimum effort to get what is wanted. Mexico is where people call in sick at work when there is a soccer match (a circus equivalent in our time) to the point that companies have to make watching the soccer match a part of work activity so people go to work.

This cultural aspect is reflected in one of the interviews. David mentioned that, in his experience, people with sight loss go to their appointment to get their disability card. This card grants them access to public transportation for free and discounts in supermarkets and pharmacies. However, when he refers them to the rehabilitation services, they do not go: *"They just take their card and leave. They are not interested in* *rehabilitating."* This ophthalmologist seemed disappointed and lost hope that people want to rehabilitate.

David's experience at the rehabilitation centre possibly reflects the culture that is present in Mexico. If people are offered the chance not to do anything, even if they could, some will take it. According to my experience as part of this culture, this way of thinking is usually related to poor access to education. As mentioned in section 1.3.2, access to education is a social barrier for people with blindness in this country.

Another possible explanation is that this reflects the internalised perception of pity in people with blindness. If society sees them with pity and as useless, not providing opportunities for them to continue being an active member of society, some people might internalise this and choose to live from the charity given to people with disabilities rather than trying to break the social barriers.

4.2.3.5 Different from "us": othering as a defence against anxiety

Another perception was a differentiation between "them" and "us". Patricia mentioned, *"They hear and feel differently. They know the world differently".* This reflection was not presented either from a better or worse position but just a different one. This could represent a recognition of difference, but could also be an attempt to create distance as a defence against the anxiety of knowing that everyone is susceptible to sight loss. This othering as a defensive reaction also appeared in the study "Seeing Blindness Through the Visual Matrix ", made as a first approach to exploring the perception of blindness (see section 2.5.2).

Andrea mentioned, "*They have many capacities"*, as if their capacities were somehow related to their sight loss. Although neuroplasticity does happen when a sense is lost, and other senses compensate for the lost abilities, this perception seems to relate to the perception that people with blindness have enhanced abilities. This may also represent a defensive reaction towards the anxiety of thinking about blindness and loss of capacity.

The othering presented from the different perceptions evidences the defences against anxiety (Hollway & Jefferson, 2008). The movement of the perceptions from "poor them" to "resilient" and then "different" shows the various ways in which the participants created distance to manage their anxiety.

This was challenging for me to write. Through writing, I kept arranging and re-arranging the themes. When writing about what upset me, I managed to secure enough distance to try to think about the defensive reaction of the participants. I find myself very angry at the ableist perception of people with blindness, particularly in placing them as "poor" and "unable" to belong to society. I was placed in that position as a proxy with my mother. After her death, I was explicitly told by my teachers at school that because of the emotional impact that my mother's sickness might have caused on me, I would not be able to do anything with my life. I was told I would end up as a drug addict, in jail or committing suicide. They wrote my story without knowing me. It enrages me that people in rehabilitation centres try to write the story for people with blindness. What they can or cannot do should not be embedded in their blindness.

4.2.4 Self-perception of the users as people with sight loss: similarities and differences between how they see themselves and how they're being seen by staff members

A shared experience was mentioned by Rolando, who was first a student at the charity and later became an instructor, and Daniela, a student at the charity, regarding the emotional impact of sight loss. Daniela mentioned, *"I felt like the world was ending, but then I went to the centre and learned that you could live. I learned computers and* *realised I was able to do things"*. Rolando said, *"It was shocking at first, but I found alternatives to keep going."*

Rolando also mentioned his perception towards the self-perception of people with sight loss as: "*They perceive themselves as unable to do anything, as a burden. They have lost their self-worth. Through the courses, they realise they can do things. They feel validated and recover their sense of worth."*

These experiences point towards a dynamic process in which they felt paralysed or unable. However, then they went through a moment of movement in which they found and developed the tools they needed to keep going via the centre or other resources. Even though some perceptions are similar to those mentioned by the staff members of the centres, such as feeling unable, those perceptions seem static when the grieving process is dynamic and ever-changing.

4.2.5 The grieving process of sight loss: a dynamic process

This section presents the perception of the grieving process of sight loss by staff members (4.2.5.1) as well as the user's experiences of the rehabilitation services (4.2.5.2). These perceptions are relevant because they reflect upon how the centre sees the grieving process of sight loss and, therefore, the relevance (or lack thereof) given to the emotional impact of sight loss. The theoretical framework of this project is based on the grieving process of sight loss and emotional support protocol created by Dr. Thurston (section 2.1) that elaborates on the adjustment of sight loss as the need to renounce to an identity as a sighted person to reconstruct a new identity as a person with blindness. The perception of the relationship between sight loss and identity was explored through the questions and is presented in section 4.2.5.3.

4.2.5.1 The avoidance of grief in staff members perception of the impact of sight loss

Interestingly, all interviewees agree that people with congenital blindness adapt more easily than people with sight loss. Within people who lose sight, they said, adjustment is easier among children than adults: *"It is easier for people born blind than to lose it. Children adapt easier. For adults, it is a complicated process. They have to adapt to a new life",* mentioned, for example, Ana. Carlos said, *"Seeing is a blessing. Sight loss is a terrible thing. It is a terrible torment, 24 hours of constant worrying."*

All interviewees also agreed that sight loss is difficult: *"It is a tough process,"* said Alex. Andrea mentioned, *"Adjustment is hard. They feel that it is over, and they are furious. Sometimes they have even thrown stuff at me, and we have to stop the class. I let them calm down and asked them what was going on. They usually answer that they are angry because they could see and now they cannot."*

This emotional response is a clear representation of the impact of sight loss that could shed light on the relevance of providing access to emotional support. *"They need visual and psychological therapy for adjustment,"* Andrea stated.

Interestingly, Patricia mentioned that *"psychotherapy is not always needed. As long as they have support from their families, they can move forward."* This perception was echoed by Ruby and Andrea, who agreed that overcoming grief depends on personality and family support.

Some people may not need emotional support to adjust to blindness. Nonetheless, I found the perception that family support is needed surprising. Family support is usually considered a positive factor in adjusting to sight loss. It would be ideal to have it, but what about people who do not have a family or whose family is not supportive? In this perception, are they condemned to being unable to adjust to blindness?

Andrea and Ana agreed that *"blindness is not a limit, it is a stone in the way, but you can remove it and move forward. Once they are over it, they feel relief."* Miguel echoed this opinion by mentioning, *"It is a small challenge, not a limitation, and the right people can help. We are here to direct them."*

It seems like the participants were avoiding to thinking about (to see) the grieving process, but were rather focusing on the adjustment to blindness.

4.2.5.2 Experiences from the users

As previously mentioned, Rolando was a student at the charity and became a computer instructor. He lost his sight when he was 14 years old. The doctors never found a precise diagnosis for his sight loss. From this lack of diagnosis, he mentioned, *"I did not understand what was happening. I found it a little difficult to grasp."*

Daniela is a student using the charity rehabilitation service who lost her sight due to a brain tumour when she was also 14 years old. She mentions her experience: *"I was furious all the time, I yelled at my mother constantly. I was very sad, I thought "now what" and cried. I felt useless and incapable. I felt that the world was ending."*

Regarding how they coped with sight loss, Rolando mentioned he did not seek emotional support: *"I think it is beneficial for some people, but in my case, I do not know what happened. The grieving process did not last long. After a month and a half, I thought I needed to go on and find ways to solve the problem. I found alternatives to continue studying. People would read to me, and I would memorise the reading and do the work. Then, I pursued a computer degree. I arrived at the centre as a student, and now I teach the accessibility of computers to others. The information is there. We just have to find how to access it."* Regarding his acceptance of sight loss, he mentioned: *"I needed to understand that I will be able to do 95% of things. Now I know. Moreover, by accepting it, I can resolve problems."*

Daniela mentioned going to the centre two years after losing sight because her mother insisted, but after the courses, she says she learnt *"many things and that you can live. Now I am happy. I laugh and talk with people. I did not feel capable, and now I even have a job."*

Along with the courses, she started going to see the psychologist because her mother suggested it: *"At the beginning, I thought 'I am not crazy, I am not going, but then I thought 'my mother would not do anything that harms me' so I went, and it helped me a lot. She gave me another perspective and became my friend."*

These situations exemplify how two people cope with the same situation differently. Although different, they both had an emotional impact, one lasting for a month and a half and the other lasting two years.

A significant difference is that Rolando found ways of pushing through by himself whilst Daniela needed her mother's support to find resources, including going to the centre, accessing psychological attention and moving through public transportation. However, this resonates with what was previously said by Patricia about family support being needed to adjust to sight loss. A question that comes up is where to place the line between support and overprotection, as it seems, in this case, that the mother is solving many things for her daughter rather than helping her to learn how to do them by herself. This is further explored in section 4.3.4.

Although both believe emotional support is helpful when coping with sight loss, neither looked for emotional support at that moment. A difference is that Rolando accepted sight loss and was able to find the tools he needed to pursue his professional development. On the other hand, Daniela did not want to go to the psychologist but instead accepted the appointment her mother made for her, which later turned out to be helpful for her adjustment process.

Rolando found a way to continue his professional development and later became a computer instructor at a rehabilitation centre. Although admirable and proof that it is possible despite the educational barriers in the country for people with disabilities (further explored in section 4.5.6), this required support not only from his family but also from the school, as well as higher cognitive skills for memorisation. The message from society to find ways to push through the existing barriers to achieving something instead of taking responsibility for addressing the barriers is further explored in section 4.5.2.

On the other hand, Daniela got her last semester of secondary school waived due to her sight loss. She perceived the Director as *"cool and supportive"* for giving her a degree she did not earn. Later, she was not accepted into a regular high school, and she had to attend a high school for people with disabilities. She did not like this school as she *"didn't like to be treated differently*", so she dropped out. She has not been able to continue studying. The educational gap and the need for inclusion in the educational sector are explored in section 4.5.6.

These experiences are a clear example of the psychological and social dimensions of sight loss. Psychological services currently provided, along with needs and obstacles, are explored in section 4.3. The social aspect of sight loss, along with the inclusion services and needs, are explored in section 4.5.

4.2.5.3 Sight loss and identity: a personal definition

During the interview, I asked participants about the relationship between sight loss and identity. This question is elicited by the literature review, particularly the grieving model proposed by Thurston (2010). This model proposes that acceptance comes from renouncing the previous identity as a sighted person and reconstructing an identity as a person with blindness. This question seeks to understand the perception of the relationship between sight loss and identity in rehabilitation centres to explore further the gap in the needs and obstacles to implementing emotional support for people with sight loss.

Most interviewees did not understand the question. They would straightforwardly reply, *"I do not understand the question,"* or, in Ruby's case, "*What do you want me to answer?"* The data-panel of experts of Mexican psychologists picked up this confusion. During the panel, they tried to get to a consensus about what identity is to understand the participant's replies. This dynamic resonates with my first Progression Exam, in which I was asked to deepen the definition I was using talking about identity. Perhaps my question was unclear, or the concept itself is too broad, but I decided to leave it that way because even misunderstanding the question is valuable data.

In those who could reply, there are divided perceptions on whether sight loss affects identity or it does not. Marycarmen established a difference between congenital and acquired blindness in relation to identity: "*If* (blindness) *is from birth, it does not affect identity because that is their identity from birth, but if they lose sight as adults, it does affect it."* Ruby mentioned that sight loss has a "*great impact on identity, and it depends on different circumstances, personal and family"*. Miguel stated that "*it impacts them because it is a disadvantage and makes them feel depressed."* Both Andrea and Ana mentioned a relationship with value rather than identity: *"It is related with self-worth"* and *"they do not lose identity, they have low self-esteem for not being able to see."* Rolando mentioned that *"it (identity) does not change"*. Then he deepened his reply by adding that he did not change. He just had to find ways of doing this differently. His tone of voice appeared cutting. This change in his voice may have been a defensive reaction as my question was addressing, perhaps questioning, his own identity and grieving process. Patricia, after not understanding the question and me explaining it, simply said no. Mariana mentioned that *"it might impact some people but not everyone."*

This opposition of ideas shows that the grieving process of sight loss, like any other loss, is not about losing sight but the meaning of sight loss to each person. Sight loss is not necessarily a defining component of identity for everyone. Therefore, the emotional support process would aim to understand the meaning of sight loss for each patient and work through their needs. The following section explores the current services, needs and obstacles for implementing emotional support in rehabilitation centres for blindness.

4.3 Where are we? Current services, needs, and obstacles for the implementation of emotional support in the rehabilitation centres for blindness

This section presents the actual situation regarding access to emotional support in the rehabilitation centres for blindness and the identified needs and obstacles of where we aim to be in making such support available.

Subsection 4.3.1 presents the perception of the relevance of emotional support as part of the rehabilitation process. Subsection 4.3.2 explores the current resources (and lack thereof) within the centres and the gaps in the psychologist's training. Subsection 4.3.3 presents the differences between what's said and done in the access to emotional support and the centre's response to the emotional reaction of the users with sight loss. As families and caregivers play a significant role in the adjustment process, subsection 4.3.4 presents the challenges and needs of working with families. Finally, section 4.3.5 discusses the users' perception of emotional support and the resistance to accessing these services.

4.3.1 Perceptions of the relevance of emotional support as part of the rehabilitation process

The perception of emotional support being "*very important"* is shared by all the participants in both centres. Some comments are: *"It is non-disposable, without a doubt." "Psychology helps understand a problem. It could be beneficial for every disability, not just blindness." "They all need the tools; psychology is a channel that helps. "Integral rehabilitation includes working within oneself."*

Interestingly, when asked about the relevance of emotional support in the grieving process of sight loss, Rolando, who earlier mentioned he did not need emotional support to go through his grieving process (section 4.2.5.2), now answered that *"it is essential"* and adds *"it would have been beneficial for me. Grieving is hard. Emotional support provides the tools to face it."* This possibly represents the resistance to define himself as a person with sight loss that could have benefitted from emotional support as he went through the grieving process.

Some participants mentioned specific issues that could be addressed via an emotional support process, such as *"emotional support is needed for parents to adjust to their child's sight loss",* mentioned by Andrea, or *"it is helpful when dealing with the social barriers,*" manifested by Ruby.

Miguel and Alex declared that "*it* (emotional support) *should be included. Psychology is part of the team."*

4.3.2 Resources (and lack thereof) within the centres: psychologist’s training as a crucial gap

In the charity centre, Patricia was invited by the Director (her friend) to work as a volunteer. She has an MSc in Family Therapy. When asked how she works with her patients, she replied, *"Not in any specific way. I just create empathy with them."*

When I asked her if the centre had any protocols to work on the grieving process of sight loss, she answered, *"There are not any specific protocols. I provide brief therapy, not 500 sessions but five or seven. If that is enough, great. If they require more than that, then it is something I cannot provide."*

I asked her if, in her experience, five to seven sessions were enough for the patients to adjust to sight loss. She replied, *"thank god, yes, they are. The centre is, wow, amazing. They work with them, so they do not need much when they arrive. They come for independence, not to work through sad stuff."* During the interview, I felt anger at her reactions. I later wrote in my reflexive journal that I thought she did not provide a space for patients to talk about their emotional reactions.

It was positive that she realised that if they needed further help than seven sessions, she could not provide it and needed to refer them to someone else. Nonetheless, alongside there not being any protocols for mental health, she could not talk about how she worked with her patients.

Regarding the psychology provision from the centre, Ruby mentioned, "*She does what she can with the resources that she has, but we urgently need to structure a psychology area, and because she is a volunteer, I cannot ask her to do much."* She mentioned that she had been trying to convince the council to hire a psychologist, but they refused. This resonates with Carlos' discourse of asking people to work for free, covered by the idea of *"helping the less fortunate to expiate one's sins"* (section 4.2.1.1). Additionally, it resonates with the centre just "showing happy faces" to the council to secure funding (section 4.2.2.1). Perhaps the need for emotional support was not evident enough for the board to believe investing in the salary of a psychologist was necessary.

However, after the interviews for this study, the council decided to hire a psychologist. Ruby mentioned that at a Council meeting, Carlos addressed the need to hire a psychologist. *"I do not know what you told him, but this finally moved. They* *agreed to hire someone part-time for the moment, and then we will see depending on the demand."* She then asked for my help as a consultant in the hiring process, training the psychologist, and building the psychology area. This is further elaborated in section 4.4.

The other centre has three hired psychologists providing attention to all the centre's patients, including patients with every disability, not just sight loss. Although they are constantly taking courses and desire to learn, legally and ethically, they do not have the credentials to treat patients. They all have a bachelor's degree in psychology, but neither is a licensed psychotherapist. In Mexico, an MSc or Specialty degree is needed to practice psychotherapy legally and ethically. Nonetheless, there is not an institution that regulates this.

There are three services provided in the psychology area:

1. Psychotherapy: provided to patients with a specific cultural and educational profile and who request the service to work through something
2. Counselling: letting the patients know someone can listen to them at any moment through their rehabilitation process
3. Supervision: Verify the patient is going to visual therapy

When asked about the everyday work inside the therapeutic setting, Mariana, who acts as the leader of the psychology team, mentioned that she *"primarily works by helping clients through the grieving process, accepting their new conditions, and developing new skills for their new life. When the patient is a child, family sessions are included in the rehabilitation plan to work through the loss of the expectation of what they wanted their child to become."* She mentions compromising with her patients beyond the centre's alignments. For instance, they are limited to working for up to 8 sessions with a patient, but if she sees the patient is still struggling, she keeps receiving them.

When asked about the methodology they used to work through the grieving process, she mentioned, *"There is not a clinical methodology used. They work through being able to handle the stages of grieving."* I then asked which grieving model was the one used at the centre. It seemed as if my question confused her. She hesitated and then answered it was the *"normal model, the Kubler-Ross model."* I followed up by asking how they worked through the stages, to which she replied, *"We just try to help them adjust to sight loss."*

In this centre, there is an important gap in the lack of training of psychologists. This is invisible as, for someone who is not a psychologist, the ethical regulations are usually unknown. I believe my question may have elicited doubts about this gap in training the psychologist as, after the interview, she asked me to train her and her colleagues on how to work with the grieving process of sight loss.

The interviews themselves helped evidence some of the gaps in the attention currently provided without me having to verbalise them. To be able to contribute to addressing those gaps gives me a sense of closure, of providing what I can to help in that more people with sight loss do not have to go through the emotional strain my mother did because emotional support was not accessible.

4.3.3 Gaps between what's said and done in the access to emotional support: centre's response to emotional reactions from the users

Neither of the Centres has a clear protocol for accessing emotional support. A critical gap was evidenced through the interviews regarding access to emotional support in the public centre. Miguel mentioned that *"everyone goes through one interview with the psychologist, and they decide the best course of action."* Ana said that "*when* *patients arrive at their courses, they have not gone to the psychology area. Some of them do not even know about the existence of psychological attention. I need to refer them."*

The answer to this gap came from David. He is the doctor who decides the rehabilitation plan for every patient with sight loss or low vision. Since he has given up hope in the patients, and his perception is that they do not want to rehabilitate but to get their disability card (see section 4.3.5 for reference), he does not include emotional support as part of their rehabilitation plan. He reflected upon this and said: *"I should refer them to the psychology area. This is important. I have not even thought about it."* This reflection made me feel that through the interview, I was able to indirectly question his perception and promote a minimal but significant change that could allow people with sight loss to access emotional support, particularly for those who come without hope of getting more than a benefit card.

In both centres, patients can request an appointment, as was the case of Daniela (see section 4.2.5.2). Nonetheless, sometimes the patients don't even know this is a provided service they can access or request.

The other way they can access emotional support is by being referred by instructors. There are no clear criteria for sending patients to the psychology area. The instructors mentioned sending them "*when they are stuck in the grieving process*" and "*when they stop going to classes or have a negative attitude."*

One of the participants from one of the data panels mentioned perceiving it was as though there could only be happy faces in the centres to keep with the image given to the council members of directors (section 4.2.2.1). When they detected a sad or angry face, they needed to send them for emotional support to turn it into a happy face again. However, without working through the person's emotional process and why they are feeling the way they are feeling.

4.3.4 Support vs overprotection: working with families

Some participants mentioned that it is common to find caregivers overprotecting their family members with blindness whilst believing they are providing support. For instance, Andrea said, "*Sometimes it is family who tells them they cannot do something. There was a time when a mom wanted to walk her son to the classroom door. I told her, 'Mommy, we need to let him do it alone. He needs to learn. She would let him do it by himself for a while but continue watching through a window. Then she understood her son is completely capable of walking by himself and arriving at the classroom.*" Then she added, *"Helping has its technique. They (parents) need to learn how to let go, not overprotect."*

This situation was embodied through Claudia, the mother of Juan, a nine-year-old child with sight loss due to cerebral palsy. The centre suggested she go for counselling to work on *her* grieving process, but she mentioned: *"I know it is important, but my son needs me 24/7. I cannot leave his side, and no one can take care of him as I do. There is no way for me to go to it."*

Daniela is on the other side of this equation. She lost sight when she was 14 years old, and until today her mother has helped her (she is now 22). *"I do not know what I would do without my mother. She grabs the bus with me, helps me get to my courses, and helps me at school. She helps me with everything. I am very grateful and do not know what I would do without her."* Her mother's help has been crucial in her adjustment and access to rehabilitation services (see section 4.3.4). Nonetheless, there are some tasks that she could explore doing on her own, such as taking the bus like her classmates from the rehabilitation centre. It seems like the co-dependent dynamic with her mother is impeding her from exploring her abilities to perform some tasks by herself and becoming independent.

The obstacle that overprotection poses in the adjustment process of blindness sheds light on the need to provide a space for families to work through their grieving process. Marycarmen mentioned, *"Overprotection is a crucial factor in working with families, how much protection to provide without it being negative. They need to work through a grieving process, or they will overprotect the child. It is not just with time. They need to work it through."* This was echoed by Ana, who said, *"Emotional support is needed for parents to adjust to their child's sight loss."*

Besides providing emotional support for families, there were ideas on additional resources that could be offered. *"We need to motivate families",* Ruby mentioned. Some ideas were to have "grieving programs for moms" and "co-dependency workshops" to address the misinformation and belief that a person with sight loss cannot do anything, and therefore the overprotection from families towards people with sight loss.

4.3.5 "I'm not crazy": perception of the users and resistance to access emotional support

Another barrier is the cultural perception towards emotional support in the country. Even though this is slowly changing, this perception is that it is still "for crazy people". This perception causes resistance to the accessing of emotional support.

Andrea mentioned that her mother asked for an appointment for her with the psychologist because she was "*seeing her very sad".* When finding out about this, she replied, *"I am not crazy, "I do not need this"*. Later, she thought it through and agreed to go to the appointment, thinking that her mother *"would not do anything to hurt her."*

From her experience after starting to get professional emotional support, she mentioned, "*It helped a lot. My mother helped me initially, but then I looked for her independently. She helps me by providing different points of view. For example, I understood that I do not have to be crazy to talk with someone."*

The perception towards mental health and psychotherapy is slowly changing to become more acceptable in Mexican culture. Nonetheless, there is still work to be done in awareness of the emotional impact of sight loss and the benefits that emotional support may bring for those who would like to access those services.

The following section explores my journey into becoming an activist during this research to bridge the gap of implementing emotional support in rehabilitation centres for blindness.

4.4 Becoming an academic activist during this research: bridging the gap for the implementation of emotional support at the rehabilitation centres for blindness

Before I started this research, I tried to evidence the need to offer emotional support as part of the rehabilitation services in one of the centres. "*Emotional support is not needed for someone to adjust to sight loss,"* was the reply (section 1.1.2).

Through this research, I aimed to explore the perception of blindness and emotional support to understand the needs and obstacles to implementing emotional support services for people with sight loss.

Perhaps the emotional impact of sight loss is clear to me because I saw it in my mother. She could never emotionally cope with sight loss. When she lost her sight in 1998, emotional support was not offered by the rehabilitation centre that provided material for us to learn braille. Neither my mother nor my family considered looking for emotional support (section 1.1). Perhaps having a space to talk about what she felt could have helped my mother work through her grieving process and adjust to sight loss. Maybe it wouldn't. Perhaps she would've decided not to talk about it. All I know is that it wasn't an option for her. For us.

I understand that emotional reactions are not the same for everyone, and not everyone needs professional emotional support to adjust to sight loss. Still, some people either need or benefit from having a space to work through the emotional process of losing sight. Perhaps it is my desire to believe my mother would have been one of them and that her life and mine could have been emotionally less painful.

Offering a place to work through the grieving process of sight loss as part of the rehabilitation plan for whoever wants to use that space has been the goal of my life project. Offering to others what I believe could have made a difference for me.

Through time, things have changed in the rehabilitation centre that had previously helped my mother and me. Then, emotional support was provided by a volunteer psychologist and then a part-time paid psychologist was hired. Given the previous resistance both the director of services and I faced incorporating psychological attention, the resolution of hiring a psychologist (even if part-time), and, as mentioned earlier, the invitation to contribute to her training and build the centre's psychology area elicited happiness and peace in me. Without trying, I was organically arriving at a place where I could contribute to making emotional support accessible for people with sight loss in the rehabilitation centre where my mother (and I) could not get it.

To have a platform to deliver this training, I developed an association named Maccia, a variation of my mother's name, Martha. This platform is dedicated to training professionals and developing inclusion projects for people with sight loss and visual impairments.

MACCIA
Construyendo otra mirada

Maccia's logo and slogan: "Building a different gaze."

Working with Dr. Thurston, we adapted the emotional support model used at the RNIB and Retina U.K. for the Mexican population. We developed a clinical training for psychologists that includes the epidemiological, social, and clinical theoretical foundations to understand the emotional impact of sight loss and the specific social characteristics of Mexico that affect this process, as well as clinical activities to practice locating the patient within the Five Stage Sight Loss Model and possible clinical interventions. This training is called *Protocolo Maccia: Acompañamiento Terapeutico en la Pérdida Visual* (Maccia Protocol: Emotional Support Through Sight Loss) (appendix 9.6.1). The theoretical, non-clinical part of this training is also offered for people to non-psychologists: ophthalmologists, visual rehabilitators, social workers, staff from rehabilitation centres, teachers, family members and everyone who wishes to learn. The recently hired psychologist and the visual rehabilitators from the charity were the first generation of the course of the Maccia protocol, which Dr. Thurston endorsed. After the course was finished, the local newspaper released a note letting the city know the charity now offered specialised emotional support for people with sight loss (see appendix 9.6.2).

Perhaps working as a consultant for free is falling into what Carlos wanted from me. Still, the recognition (after nine years) that emotional support is a helpful tool for someone to adjust to sight loss and the opportunity to provide knowledge so that emotional support is offered in the right way, although not monetary, is enough payment. I can finally close the circle and repair in others what I could not address as a child with my mother.

Additionally, working with this psychologist, we are building the inclusion area of the centre, aiming to promote access to education and jobs for people with blindness and visual impairments. The inclusion of services and their obstacles are explored in the next section.

4.5 What's next? Inclusion services and their obstacles

This section presents the current services, obstacles and needs for including people with blindness in society.

Section 4.5.1 offers the society's attitudes towards people with blindness that provides a possible explanation for the gaps in the inclusion services. Section 4.5.2 presents the ignorance of the Social Model of Disability manifested through the interviews with the idea that you can get through the barriers if you push hard enough. Section 4.5.3 mentions the inclusion services provided. Section 4.5.4 reflects the hidden goal within "inclusive" companies, such as saving money and reducing taxes. Section 4.5.5 explores the ableist perception within the centres towards inclusion, which entails working at a factory to get "a little money" and "feel useful". Section 4.5.6 mentions the educational gap and the need for inclusion and awareness at all levels of education. Section 4.5.7 deepens the importance of awareness and notes the current efforts made by the centres.

4.5.1 Not seeing and not wanting to see. Projections from society towards people with blindness within the rehabilitation centres for blindness

A shared perception between the staff members was that society perceived people with sight loss as "*a burden, useless and incapable." "Both patients and their mothers have told me that is how society sees them,"* mentioned Miguel. Another perception was that society sees them with "pity" and as *"little and weak. 'I will help you, poor you. They see them as weak and think, 'I am superior.'"* There is also the perception that society sees them with "compassion" and "wanting to help", but "they are *afraid because they do not know how to help. They do not know what to say or do."*

Most interviewees agreed that there is a "lack of information" about disabilities. On the other hand, Marycarmen mentioned, *"There is a lot of information, but it is scary. What we do not understand scares us. The further away, the better. We think it is not going to happen to us."* Alex stated, *"(disabilities) is not something you want to see. There is no contact until it is in your immediate circle. There is no information in schools. Everyone lives in their world. If you are not in a world with disabilities, you just do not see it. We do not want to see the crude reality; we want to live in fantasy. Patients have said, 'I have seen the building, but I did not know what it was until I brought a family member. Seeing it implies accepting that we are potential users."*

Ana was moved from working with physical rehabilitation patients to working with people with blindness and visual impairments. She mentioned that before she worked with them, she thought patients with blindness were as those that needed physical rehabilitation. *"But when I started working with them, I realised their disability is not physical; it is social."* Adding to this, Rolando mentioned, *"There are few places we can go to",* and one of the psychologists mentioned that the *"surroundings have an impact in the development of the limitation." A statement that speaks of the social model, even though this is not known as a model in Mexico.*

4.5.2 Pushing hard enough to get through the barriers: the ignorance of the social model of disability

When Rolando started working at the centre, he was given a role model position. Ruby tells students that *"they can be independent if they make an effort"* and *"if he could do it, then anyone can." "He even went to the soccer world cup in Russia by* *himself",* she told me, *"You know how confusing those international airports are. He is truly an example."*

Although he is an example of pushing through the social barriers, he also had unique conditions that not everyone has. He was allowed to continue studying because he knew how to use a computer; most schools would not allow the student to continue (the educational gap is further explored in section 4.16). He also has superior cognitive skills to memorise what those around him were reading to him to do the work.

Placing him as an example and saying that breaking through the social barriers and adjusting to sight loss depends on the effort made by the person is an ableist position. It ignores the unique traits and difficulties of each person and denies our responsibility as a society in placing those barriers and our commitment to breaking them. "*Society is not adapted for people with disabilities",* mentioned the rehabilitator's coordinator, *"we need to find ways for them to adjust to a society that's not adapted to them."*

As I was doing the interviews, these comments filled me with rage. Why do "they" have to find a way to adapt to "our" society? Aren't we all members of the same community?

The following section explores the inclusion services provided by the centres.

4.5.3 Inclusion services provided

The inclusion services of the public centre aim to find job opportunities for people with disabilities. "*The goal of the inclusion services*", mentioned Alexa, *"is for people with disabilities to be independent when the caregiver is no longer present."* This comment defining the area's goal elicited the perception in me that people with disabilities are thought to be capable of being independent "only if and when they need to" and not because they want to. This perception is the first barrier they face in terms of inclusion.

Statistically speaking, 10% of the total population of the centre have a visual impairment, from which 3.2% have sight loss. From those numbers, only men have approached the inclusion services. *"Women stay at home",* Alexa mentioned. This is directly related to the Mexican macho culture in which the men are the ones who work, and women stay at home to do domestic chores and take care of children (if any).

The way the inclusion area works is that when patients are done with their rehabilitation process, they can go to the inclusion area, where they will take cognitive and skills tests to create a portfolio that will later be matched with job vacancies.

On the other hand, the Centre either looks for companies or receives requests from companies that want to become inclusive. Marycarmen, along with the psychologist in charge of performing the skills testing, an architect and a medical doctor specialised in rehabilitation, visit the company. The architect reviews whether the company is infrastructurally adapted for people with disabilities to work at that facility and makes suggestions (if needed). If the company decides to go through with the modifications, an incentive is given to them. The medical doctor reviews the job vacancies and determines which types of disabilities are not a limitation for the job. Later, the job vacancies will be matched with the portfolios of people whose disabilities are not an impairment for the job to apply to the company's hiring process.

One of the challenges faced by people with disabilities within companies is the resistance to incorporating people with disabilities: *"They're afraid of them, they don't know what to do or how to treat them, so they close their doors to them. We try for companies to give them the opportunity and show them they can do the work,"* mentions Alexa.

Another obstacle that she mentioned is that companies that hire people with disabilities treat them in a special way: *"we tell them to run the normal process, that having a disability is not being special. We want them to treat them as any other* *person." "Companies tell us they're having a party for when they start the job. We ask them, 'is this something you do with every employee?' No, they say. 'Then why are you doing it with them?'"*

To fight this stigma, the inclusion area promotes awareness workshop at companies that aim to inform about disabilities, breaking the ableist perception and promoting social inclusion. *"Some people have liked a job, but they resign because they feel excluded by their co-workers. The co-workers don't know how to treat them."* The workshop includes activities so people "live with a disability" to promote awareness, as well as to reflect upon what being inclusive means and how to treat people with disabilities: *"for instance, we tell them 'you wouldn't like to be ignored, or pushed or pulled in a wheelchair.'"* Alexa mentioned: *"they* (people at the companies) *like the workshops a lot because they show them something they haven't considered."*

The following section explores the undisclosed benefit within the companies to become inclusive.

4.5.4 Saving money and reduced taxes: the hidden goal within "inclusive" companies

Another obstacle faced by people with disabilities is that sometimes companies mention they're inclusive. Alexa mentioned two examples of these obstacles. One of them is that companies hire people with disabilities in the same position as someone without a disability and pay them less. *"Some companies believe that it's a way to save resources. We try to fight it, but it's still happening,"* she mentions. Another reason is that they want to be seen to be inclusive, more than actually caring about offering appropriate opportunities: *"Sometimes they ask for someone in a wheelchair for the reception. We tell them it could also be another kind of disability, but they want a person in a wheelchair, so it's evident that they're inclusive."* However, being inclusive includes a lot more. It requires inclusive infrastructure in the place of work, ensuring that the activities in the job position can be done by a person with a disability, and generation awareness and an inclusive attitude from coworkers towards people with disabilities,

The next section explores the conscious and unconscious perception within the centres regarding people with sight loss having job opportunities.

4.5.5 The conscious and unconscious perception within the centre regarding work inclusion. Working at factories: the only option to get "a little money"

One of the things that got my attention was skill testing. The psychologist in charge of the testing showed me the tests used for people with sight loss or visual impairment (Appendix 9.6.3). It was surprising that all the tests aimed to evaluate if they could perform manual work, such as putting together piece A with piece B or moving a piece from spot A to spot B. None of the tests was aimed to evaluate people with professional careers but rather seemed only aimed at people without formal studies that might work at factories. Why is it assumed that people with a disability don't have formal studies?

This resonated with what Miguel said in his interview: *"It's good that they can get their 'little job' so they can earn their 'little money and feel productive."* It seems like it's assumed that people with disabilities wouldn't have formal education and couldn't afford a 'big job'.

If the person had a limiting result on the tests, the area provides workshops to develop different skills, such as painting, balloon twisting and making pinatas. *"Before the pandemic, the government gave them scholarships for workshops and an incentive to start their own business,"* explained Alexa. These workshops elicited anger in me because, culturally speaking, those are skills that aren't going to lead them to a formal job or to have their own business. Still, they're in line with them "*having little jobs",* as Miguel said. Why, if the results from the tests were limiting, is that person not referred to a formal educational service?

The next section explores the educational gap for people with disabilities in Mexico and the need for inclusion and awareness at all educational levels.

4.5.6 Educational gap: the need of inclusion and awareness at all educational levels

Educational inclusion is not a service promoted by the public centre. The public centre does not have the possibility of fostering educational inclusion, given the educational system is not offering the support needed by people with disabilities. Some school leaders may allow students to remain in mainstream rather than specialist provision, as in the case of Rolando, but this is not common or policy.

"Teachers don't know what to do, and the government doesn't want to invest in training them to work with children with disabilities," mentioned Alexa.

Regarding this educational gap, Rolando mentioned having the opportunity to continue studying but having to find extraordinary measures, like memorising what was read to him to be able to do the work.

Daniela mentioned that her "teacher was cool", and he gave her the diploma even though she didn't finish the cycle. Interestingly, she found that action as something nice from him when it is an ableist position to provide a certificate she didn't earn. After getting her secondary diploma, her mother enrolled her at a high school for children with disabilities, but she dropped it because she wanted to attend a regular school. She registered, but when the pandemic started, there weren't resources to keep guiding her in her online classes, so she dropped out of studying. Now, she hasn't returned to her studies.

Although having a special school setting might be necessary and/or beneficial for children with some disabilities, generalising that every child with a disability would have to go to a specialist school or that they wouldn't be able to adjust to a regular school might be segregating. The decision should be made by understanding the child's needs and where they would be addressed in the best way possible so the child can develop as well as possible. Deciding that children with disabilities would have to go to a specialist school because they have a disability may amount to unnecessary exclusion and segregation. Believing this as necessary for all those with disabilities might shed light on what is being referred to by the adults working alongside people with disabilities: "*They don't know how to treat them.*"

The *Ley General para la Inclusion de las Personas con Discapacidad* (General Law for the Inclusion of People with Disabilities) in Mexico states that education can't be denied to children under any circumstances. Sadly, no one is enforcing that law and making sure it happens. For educational inclusion to occur, the government would have to make sure the law is followed and invest in the education of teachers at all academic levels.

Claudia, Juan's mother, mentioned that she found discrimination at private schools: *"if they accept the child, it's with a personal teacher and if there's money in the deal."* She enrolled her child in a public school, where he is included in a regular classroom: *"they adapt the activities for him, of everyone else is doing 3-digit sums, he's doing a 1-digit sum."*

"I'm not asking for results from the school, only that they're included, that they don't get treated differently. I'm only asking for a chance," she says. Besides the inclusion of children at schools at every educational level, Alexa mentioned, *"this is an important subject that should be included in education to children. For example, deafness wouldn't be a disability if sign language was taught to children"* The inclusion

of those subjects at school would organically create the awareness needed for when those children grow. The inclusion of people with disabilities would be normalised.

4.5.7 The importance of awareness: workshops provided by the centre

Almost every participant mentioned there's a "*lack of awareness*" of disabilities (section 4.11). The public centre has created awareness workshops that are promoted at schools, companies and cultural and sports spaces. These workshops include theoretical information about disabilities and activities to create awareness, such as going through daily activities in a wheelchair or blindfolded. At the end of the workshop, a space is provided to reflect on the barriers they perceived and generate ideas on what to do to break those barriers. *"People like these workshops because they learn and experiment with life as if they had an impairment. We've received positive feedback about them"*, mentioned Alexa. The challenge of these workshop is that the interested school or company has to seek for the centre to implement it at their venue.

Although the centre's efforts towards inclusion are a great start, there's still a lot of work to do. If we could tackle access to education at all levels, work inclusion wouldn't be so complicated, and awareness workshops would be less needed. This is, of course, a project that would require time, effort, and resources, and it would show its effects in the long term, when it's “no longer useful” (see section 4.2.2.2). I believe this is the social barrier inclusion faces.

4.6 Conclusion: the research journey

The findings of the interviews and my reflexive journal reflect my journey through the PhD. From my personal experience and my previous academic journey (sections 1.1.1 and 1.1.2), I knew there was a lack of access to emotional support to go through the grieving process of sight loss in the rehabilitation centres. When I started this project, I wanted to address this lack by exploring the perception of sight loss and its link to the lack of emotional support to understand the needs and barriers to implementing this service.

When exploring the perception towards people with blindness, I found that, in general, there's a prevalence of feelings of pity, and the charity model of disability influence significantly the perception towards people with blindness (section 4.2).

When I arrived at the centres to conduct the interviews, I realised they had implemented some emotional support. Through the interviews, I explored those services to understand the needs and obstacles they were facing. I found some gaps needed to be addressed, such as the psychotherapists' training, the access to emotional support in the rehabilitation plan, working with families and the users' perception of emotional support (section 4.3).

The interviews themselves seemed to have helped evidence some of the gaps in the attention currently provided without me having to verbalise them. The council member of the charity centre decided to hire a psychologist and asked for my help training her and building the psychology area. In the other centre, the psychologist working with people with disabilities asked for my help training them to work with people with sight loss.

This is something that psychosocial research has been known to produce in participants, raising the questions triggers reflection that in turn can turn to positive action. On a personal level, it meant I was organically arriving at a place where I could contribute to making emotional support accessible for people with sight loss in the rehabilitation centre where my mother (and I) couldn't get it. I feel like I can finally close the circle and repair in others what I couldn't address as a child with my mother (section 4.4). This is an ongoing project through which we're now training psychologists that wish to learn how to work with people with sight loss and developing inclusive projects for people with sight loss and visual impairments. Although this project is still regional, it is nonetheless pioneering work in Mexico and hopefully it might go beyond the city I'm at and expand to the rest of the country.

After exploring and being able to address the access to emotional support in the rehabilitation centres for sight loss, the next question came naturally to my mind: "once a person with sight loss has emotionally adjusted to this loss and acquired tools like braille, use of the cane, computer, daily life activities, etc., where is this person adapting?" This question led me to explore the inclusion services and their obstacles (section 4.5). Interviewing Alexa I realised that, although services are provided for people with disabilities to access jobs (section 4.5.3), there are many obstacles in terms of inclusion. Lack of information and awareness of the social model of the disability leads to the belief that if people with disabilities push hard enough, they will get through the barriers instead of addressing the barriers themselves (section 4.5.2). Also, the permeated feelings of pity through the belief that companies are doing towards people with disabilities by hiring them (section 4.5.5) and the benefits the companies get for being "inclusive" (section 4.5.4) enhanced the ableism towards people with disabilities. Additionally, there's limited access to education for people with disabilities at all levels, and no one is currently addressing this gap (section 4.5.6). Addressing the gaps in the inclusion services for people with disabilities is a massive task.

My position has shifted through this journey from a student researcher to an activist, and the goal I had set when my mother died has transformed. I wanted to make the emotional challenges of adjusting to sight loss visible and implement emotional support as part of the rehabilitation process. I understand now that emotional reactions are not the same for everyone, and not everyone needs professional emotional support to adjust to sight loss. Still, some people might either need or benefit from having a space to work through the emotional process of losing sight, and I still believe it's a service that should be offered to whoever wants to take it.

The following chapter (5) theorizes on the transition from the psychological to the social dimensions of sight loss, discussing the data presented in this chapter (4) and its meaning in relation to both the reviewed literature (chapter 2) and my journey through the research (chapter 3).

5.- Discussion

5.1 Introduction

As mentioned in section 1.1, this research was prompted by my experience of being my mother's carer through her grieving process of sight loss and the absence of emotional support available for her and me at the time. As researchers, we cannot detach our subjective involvement. There is a reason why we research what we research. We must accept and examine the role of our history and subjectivity in our research process. The more we understand ourselves and the reason we do what we do, the more we will be able to inform how we interpret the data (Hollway & Jefferson, 2013).

The concept of *survivor guilt* is used to describe feelings of guilt a person may experience when they survived a loved one or a traumatic event in which people were harmed or lost their lives. This feeling of guilt is produced by the empathic concern for the person suffering and the belief that an action or omission, real or imaginary, is hurtful to another person (Fimiani et al., 2022). When my mother died, I felt I failed to keep her alive long enough to find a cure for her blindness, and it was hard for me to cope with the idea of being alive when I felt responsible for her death.

After grieving for losing my mother, I understood that I needed to elaborate and transform my experience. I realized that I did not fail in healing her blindness, something I could not have done, but in helping her accept and adapt to it.

The term *wounded healer* suggests that healing can emerge from a healer's woundedness. Woundedness is a continuum. What is relevant is not the degree of woundedness but the ability to draw on that woundedness for the purpose of healing (Zerubavel & O'Dougherty, 2012). Since my mother's death, I set my mind to understanding the grieving process of sight loss and doing *something* so that people going through this process do not have to go through the emotional strain we did. I have been using my experience and woundedness to provide a way to work through the emotional impact of sight loss, something my mother and me didn't have.

This study is a crucial part of that understanding and transformation as it represents the transition from a focus on the personal psychological impact of sight loss (my starting point- see section 1.2 for further reference) to the role of social perception, attitudes, and structures that define the place people with blindness have in society. These perceptions, in return, influence the psychological impact of sight loss. This research aimed to shed light on the current situation regarding emotional support for people with sight loss in the rehabilitation centres for blindness in Mexico by addressing the following questions:

1. What is the perception of blindness and the grieving process of sight loss in a rehabilitation centre for blindness, and how was this perception constructed?
2. From this perception, what emotional support services are provided by rehabilitation centres for blindness?
3. What would be the needs and obstacles for implementing emotional support in rehabilitation centres for blindness?

The previous chapter (4) provides the findings that address these research questions. Section 4.2 presents the perception of sight loss inside the rehabilitation centres and how this perception was constructed (research question 1). Section 4.3 presents the current services, needs and obstacles to implementing emotional support at the rehabilitation centres for blindness (questions 2 and 3).

Additionally, as emerging themes during the research's journey, section 4.4 presents my efforts to implement psychological attention inside the rehabilitation centres for blindness, and section 4.5 presents the current inclusion services and obstacles.

Thus, after presenting the findings and emerging themes, this chapter theorizes on the transition from the psychological to the social dimensions of sight loss, discussing the data gathered from the study (chapter 4) and its meaning in relation to both the reviewed literature (chapter 2) and my journey through the research (chapter 3). It follows the premise of psycho-social studies: psychological issues and subjective experiences cannot be abstracted from societal, cultural and historical contexts, nor can they be deterministically reduced to the social (APS, 2023_a).

Section 5.2 discusses, through an intersectional lens, the Mexican cultural context in the production and maintenance of the perception of blindness in the rehabilitation centres, traced to the Spanish colonisation and the establishment of the Charity Model of Disability.

Considering the Mexican cultural context, section 5.3 challenges the impact of sight loss on identity by presenting a re-conceptualization of the grieving process of sight loss from a psycho-social perspective.

Section 5.4 critically reflects on the methodology used for this study, presenting what I believed was helpful from the selected methods and what I could have done differently or would now do differently.

Section 5.5 reflects upon the impact of this research in questioning the current perceptions towards blindness in the rehabilitation centres in Mexico, thus leading to the implementation of emotional support for people with sight loss in the rehabilitation centres.

Although this research aimed to explore the perception of blindness and emotional support in rehabilitation centres to understand the needs and obstacles of implementing emotional support for people with sight loss, the natural progression of the study led my thinking and questioning towards inclusion. Once a person with sight loss has gone through a process of rehabilitation and has emotionally adjusted to blindness, I turned my gaze outside the centres to find a society filled with barriers that *disable* a person with blindness from belonging to the community. Thus, section 5.6 takes a step further from the original aim of the study. Considering the results from section 4.5, which shed light on the social obstacles towards inclusion, and linking those obstacles to the perception of blindness based on the Charity Model of Disability (section 2.4.4), this section discusses inclusion for people with blindness through the lens of Disability Studies.

Additionally, section 5.7 discusses, through the theory of colonialism of Frantz Fanon, the silent resistance of people with blindness and other disabilities to use the Charity Model of Disability to create a non-registered organization to earn an income by begging on the streets to elicit pity and a charitable reaction.

Finally, section 5.8 presents the challenge of the Social Model of Disability towards people with blindness in Mexico: breaking not only the barriers but the perception that produces and maintain the barriers.

Through this chapter, I will be referring to *blindness* as the absence of sight, either congenital or acquired and as *sight loss* to the *process* of losing sight. Therefore, a *person with blindness* or *blind person* refers to a person that cannot see, whilst a *person with sight loss* refers to someone that is going or has gone through a process of losing sight.

5.2 The Spanish colonization and the Charity Model of Disability: The Mexican cultural context in the production and maintenance of the perception of blindness

As mentioned above, this study represents a transition from researching the emotional impact of sight loss to exploring the social perceptions towards blindness. When I started my doctoral studies, I had not considered the cultural context and the extent to which it can impact the process of sight loss. Nonetheless, through this research, I have understood the significant role social perception has in the emotional impact of sight loss and, therefore, in the adjustment to blindness.

In this section, I discuss, through an intersectional lens, the social associations towards blindness found in this research (chapter 4), theorising about the construction of the Mexican social unconscious since the Spanish colonisation that led to the implementation of the Charity Model of Disability (section 2.5.1), which still stand today as the baseline for the perception towards people with disabilities in Mexico.

This section addresses the first research question: What is the perception of blindness and the grieving process of sight loss in rehabilitation centres, and where did this perception come from?

According to Penna (2022), the social unconscious is a discourse which hierarchically orders other discourses. Since the colonisation of Mexico by Spain, a traumatic experience was imprinted in the collective unconscious of the Mexicas. To force the natives into their religion, the Spanish destroyed monuments connected with traditions and collective memory. They buried the Mexica's pyramids, placing Christian churches on top of them with a glass floor so natives could see their buried sanctuaries. The Mexicas were forced to pray to the Christian god or be murdered. This process is coined by Hernandez de Tubert (2021) as the *myth of the conquest*. This discourse sustained the fantasy that, instead of destroying the native culture, the Spanish, as a superior race, were "civilizing" the natives, i.e., saving them from ungodly pagan practices. This discourse, Fanon would say, justified the uneven division of resources (Fanon, 1967). This myth is imprinted in the social unconscious of Mexican people. Since then, and through time, it has become one of the worst sins to question the Christian religion, let alone renounce it.

During the colonial era (1524- 1859), hospitals, nursing homes, orphanages, hospices, and houses of mercy were built. The treatment for people with disabilities adopted the Charity Model of Disability. This treatment was ambivalent as it had, on the one hand, the discourse of compassion from the Christian charity and, on the other hand, exclusion and punishment, as disability was associated with a malefic origin, such as a sin, mental illness or witchcraft. This model is thought to have permeated up to 1859, when a new law declared that the charity centres under the control of religious institutions become the state's property, thus giving way to the Medical Model of Disability era. Nonetheless, characteristics of the Charity Model are still present today, such as identifying people with disabilities as objects of charity and compassion, forced sterilisation and social exclusion (Sandoval et al., 2016).

The research results showed that the perceptions towards people with blindness from both centres are based on the Charity Model of Disability. Overall, there is a general perception of people with blindness being "less fortunate" and "needing help" (section 4.2.3.2). Additionally, there is a recognition of resilience and *bravery* towards people with blindness, potentially based on the frightening characteristics of the associations towards blindness and the admiration for those living with it (section 4.2.3.3). Nonetheless, people with blindness are still identified as "different" or "the other" (section 4.2.3.5), which serves to create distance and the self-denial of being excluded from the possibility of sight loss: "the other" is less fortunate, "the other" needs help, "the other" is being brave through this. "I" have to help them.

Walsh (2020) mentions that the *Saviour Mentality* is defined as wanting to help others but not being willing to receive guidance from those you want to help. This mentality is based on power relations such as racism and colonialism and is often embedded in charitable activities.

This research was conducted in the north of Mexico, where most Spanish immigrants settled after the colonisation. European last names are prevalent in this area. Also, economically, this area has a greater gross domestic product than all Latin America (Coneval, 2020). It is not uncommon that the descendants of European immigrants are the leaders of companies or, in this case, rehabilitation centres.

On the other hand, the users of the rehabilitation centres for blindness are primarily people with low income. This disparity can be explained by visual health not being part of the primary health plan. Therefore, access to visual health services is limited to whoever can pay for them. The leading cause of blindness in Mexico is cataracts (88%), a reversible condition (Cámara de Diputados, 2020). The high prevalence of a treatable condition speaks of the lack of access to medical care and the absence of awareness and educational programmes about common and curable causes of sight loss.

Meekosha (2010), proposes that an impairment can be defined as a "social product". For instance, the aim to control resources such as oil can lead to dangerous working environments that could result in disease and injuries. Additionally, lack of access to medical treatment can make impairment a social product.

Recent global perspectives incorporated the role of colonisation and colonialism as disabling and devastating experiences for the colonised. Additionally, from a global perspective, the prevention of impairments as social products incorporates the role of the global north in "disabling" the global south. This perspective leads to asking, as Meekosha does: "why disability and poverty are so interrelated in the global south? (Meekosha, 2010, p. 671).

Intersectionality is a theoretical framework for understanding how aspects of a person's social and political identities combine to create different modes of discrimination and privileges. This term was coined by Crenshaw in 1989 to shed light over the double discrimination of racism and sexism faced by Black women. "Black women", she mentions, "sometimes experience discrimination in ways similar to white women's experiences; sometimes they share very similar experiences with Black men. Yet often they experience double discrimination- the combined effects of practices which discriminate on the basis of race, and on the basis of sex. And sometimes, they experience discrimination as Black women- not the same of race and sex discrimination, but as a Black women" (Crenshawe, 1989, p.149). When categorising the discrimination towards Black women as gender or race, both the juridical system and civil rights organisations fail to recognise their unique situation, hence their experiences are absorbed into the collective of either group or as different from each group, falling into an in-between place where their experiences are not recognised and their needs are not met.

Although the term was created to shed light over the specific intersectional discrimination of race and gender faced by Black women, Crenshaw (1989) defines intersectionality as a metaphor for understanding the ways that multiple forms of inequality or disadvantages can compound themselves and create obstacles that are misunderstood among conventional ways of thinking.

From a psycho-social perspective, Crenshaw's framework highlights that intersectionality is not merely an observation of the various intersections of identity (race, gender, class, sexuality, disability) but also a critique of the ways in which social structures contribute to the system inequity experienced by individuals who occupy multiple marginalised identities (Collins & Bilge, 2016).

If we think about disabilities in Mexico from an intersectional perspective, it becomes clear that people with disabilities in this country are not just marginalised by their impairments but are also placed in the intersection with class. Class, in Mexico, defines the access or barriers to resources, opportunities and support systems. As previously stated, lower socioeconomic status is associated with less access to quality healthcare, education and employment opportunities, barriers that are maximised by individuals with disabilities. Following an intersectional premise, people with disabilities in Mexico can sometimes experience discrimination related to people with an impairment, and they can sometimes experience discrimination related to their social status. However, an intersectional framework demands us to think about it not as one or the other but as a unique discrimination configuration sitting at the intersection between disability and class.

In the waiting room of the charity centre, there is an image of Jesus of Mercy. This image could hold the unconscious meaning of the centre being merciful to people with blindness, thus positioning themselves as saviour father figures. In agreement with this position, Carlos, the member of the Council and the Director of the centre, mentioned feelings of pity towards people with blindness, calling the children who are going through a rehabilitation process "little angels". The perception is that "they are less fortunate, and we have to help them" (section 4.2.3.2). As mentioned earlier, the council members and directors belong to a high-income class while the users belong predominantly to a low-indome class. Aligned with the Christian discourse of compassion, by using this approach, they get donations from pity and guilt under the premise that by helping the centre, people will earn their place in heaven. "Someday, we are going to be asked to provide an account of what we did. We must help to earn our place in heaven," was mentioned in the interview with Carlos.

Carlos mentioned he only saw happy faces: "I promise you I have not seen any sad or angry faces. The centre is truly doing a wonderful job". His experience did not make sense with my experience walking beside my mother through her sight loss and all the emotional reactions it entailed for her. Nonetheless, when interviewing Ruby, the Director of the Educational Area of the Charity, where the rehabilitation services take place, she mentioned that they "have to show the Council the positive outcomes, so they keep donating" (section 4.2.2.1). I understood then that it is not that people with sight loss in the charity are not having any negative emotions, as Carlos thinks. Ruby is hiding the people who have negative emotions and showing only the "success" cases (as if "success" equals not feeling negative emotions) to the Council with the idea of it being the way to secure further funding through their donations.

I asked the instructors what happens with people with negative emotions throughout the courses. They replied that they sent them to Patricia, the psychologist working as a volunteer at the centre. Patricia is a friend of the Director of the centre. When interviewing her, she said that people going through a rehabilitation process at the charity were there to "be autonomous, not to talk about the bad stuff" (section 4.3.1). Apparently, she was there to listen to the patients but did not provide any emotional support. One of the users who worked with her referred to her as "the friend she talked with" (section 4.3.3). Simply, there does not seem to be a place to talk about the negative emotions people might be feeling.

This information answered the initial question that led me to develop this research: Why was the Charity saying emotional support was not needed for someone to adjust to sight loss? The Council Members could not see the need to include emotional support because they "only saw happy faces" (section 4.2.2.1).

This dynamic leads us to question: Why are *negative* emotions so unbearable? Why do they need to be hidden away? Freud (1905) used the term *defence* to indicate a person's attempts to ward off an unacceptable idea that may cause distress (anxiety). He later differentiates *denial* and *disavowal* as two defences against anxiety. *Denial* was defined as the psychotic's rejection of reality, whilst *disavowal* is a process in which reality is registered and acknowledged. However, the significance is refused as it is too anxiety-provoking.

Menzies Lyth (1960), when studying the splitting phenomena in nurses in World War II, theorizes that the need to relieve the members of a system from intense anxiety leads to the development of structured defences. Change, therefore, threatens the existing social defences.

Perhaps, the fear is that if they let the Council Members *see* the emotional strain that sight loss can cause to some people, it might be too anxiety-provoking, and he might choose *not to see* and withdraw his donations. As if the fantasy is that he was paying to see happy faces, *rehabilitated* faces, and not to support *the process of rehabilitating*.

The rejection to acknowledge the emotional impact of sight loss could also be based on the cultural and historical associations towards blindness. Since the word blindness was coined, it has been associated with darkness and death (Von Klein, 1905; Güemez-Sandoval, 2009), making sight loss terrifying (see sections 2.4.2 and 2.4.3 for further reference). Sight loss is the third most feared condition, after cancer and heart failure (The Eye Associates, 2022). This resistance to *seeing* the emotional impact of sight loss may be related to the denial (or disavowal) of the possibility of losing sight and the creation of a fantasy in which sight loss *is not so terrible, as there are only happy faces to be seen*.

The belief that people with blindness have "better" or "higher" attributes (section 4.2.3.5) can represent another defence for the anxiety evoked by facing the possibility of losing sight, mainly when working with people with blindness. This belief transforms the idea of a loss into the fantasy of acquiring better skills (Larrissy, 2007). This theory was also confirmed in a previous study that explored the perception of blindness using the Visual Matrix Method in bachelor's students in the second semester of psychology. In this study, the alumni associated blindness with "enhanced" and "different" abilities as a defence reaction towards the possibility of losing sight (section 2.5.2).

Another association that appeared in that study, prompted by a picture of blind eyes, was the relationship between blindness and death: "There are like dead eyes, but alive", a student mentioned. This association leads to reflecting on a possible social unconscious association between blindness and death (Von Klein, 1905; Güemez-Sandoval, 2009). Additionally, this phrase suggests that blind eyes could be associated with dead eyes as neither can offer a reflection.

People with blindness cannot provide a visual mirror through which sighted people can feel reassured. This relates to the theory of sight being the channel through which a person builds their identity by reflecting in their mother's eyes (Winnicott, 1971), a process that is repeated through life as we constantly rebuild our identity upon the gaze of others (mostly a visual gaze for sighted people).

Once I heard a psychoanalyst who worked as a therapist at a rehabilitation centre for blindness talk at a conference. She mentioned feeling enraged for not being seen by her patients and, therefore, not feeling recognised as a counsellor (Ponder, 2016). Evgen Bavcar, a photographer with blindness, also elaborates on this association. He carries a small mirror as he knows that seeing demands, in return, the desire to be seen. Knowing he cannot provide the specular gaze people with sight are used to, he places the mirror for those around him to find themselves and feel reassured (Mayer-Faulkes, 2014).

What seems to be elicited by this anxiety (and rage) is a primitive reaction to the lack of visual cues that offer recognition and validation. This relational need is not forthcoming in the way it is expected, which could be unconsciously perceived as an attack manifested as the reluctance to be recognised by a person with blindness in the way sighted people need to be recognised: visually. Perhaps the rejection *towards* people with blindness is not because of an *othering* prompted solely by their visual impairment but as a defensive reaction *from* feeling rejected, unrecognised, by people with blindness. "He who is reluctant to recognise me opposes me" (Fanon, 1967, p. 218). Hence, we are stuck in an ongoing defensive position in which no one can recognise and validate the other.

Additionally, perhaps the resistance of the Charity centre to acknowledge the emotional needs of people with sight loss is related to receiving happy faces as the only gratifying return for the help they provide, therefore reflecting and re-constructing their identity as saviours.

On the other hand, in the public centre, the rehabilitation services appear to be based on the Medical (or rehabilitation) Model of Disability. As mentioned in section 2.4.4, this model perceives disability as a flaw that must be corrected (Sandoval et al., 2016). As sight loss is seen as a terrible thing that cannot be cured, it is not worth investing in rehabilitating people with it. Alex, the Rehabilitators' Coordinator, mentioned that "it is more visible to invest in things that can heal, such as an injury in someone who cannot move their hand and then they can, than in things that will not heal" (section 4.2.2.2). This supports the Rehabilitation Model of Disability in terms of having to heal the impairment, and if it cannot be healed, the person with it is discarded. Nonetheless, underneath the perception based on the rehabilitation model of disability, there is also an unspoken perception of pity towards people with sight loss for having a condition that cannot be cured, which brings us back to the Charity Model of Disability.

The perceptions found at the rehabilitation centres for blindness seem to be the "institutionalisation of social power relations in the structure of the psyche itself" (Dalal, 1998: p.21). The Council Members and Directors of the centres perceive themselves as superior and saviours, "helping the poor people with blindness" (section 4.2.3.1 and 4.2.3.2).

Once a visual problem has progressed to the point of sight loss, the rehabilitation centres take on the role of merciful saviours, providing access to rehabilitation services at a low cost. This action can be related to the concept of tithe or indulgences. The definition of the tithe is giving money to the church to support it, but underneath the goodwill of helping the church, it was supposed to "buy" a place in heaven. That visual health is not recognised as primary health enhances this superior position in a never-ending cycle.

The repetition of this social dynamic via the collective and intergenerational unconscious configuration of the Mexican population directly affects the perception towards people with sight loss and their self-conceptualisation. People with sight loss are perceived (and doomed as) useless *because of* their sight loss, which directly affects their adjustment process to blindness.

Rolando, the computer instructor from the Charity (with sight loss himself), mentioned his perception towards the self-perception of people with sight loss: "They perceive themselves as unable to do anything, as a burden. They have lost their self-worth. Through the courses, they realise they can do things. They feel validated and recover their sense of worth." The interviewees mentioned a shared experience with sight loss: "I felt like the world was ending, but then I went to the centre and learned that you could live. I learned computers and realised I was able to do things. It was shocking at first, but I found alternatives to keep going" (section 4.2.5.2). This initial shared perception of the world ending could be unconsciously related to the social exclusion in the Mexican culture: "The world is ending because I do not have a place as an equal in the world *(my world*) anymore." This is further discussed in the following sections 5.3 and 5.4.

We have explored in this section that the Mexican social unconscious plays a role in creating and maintaining associations towards people with blindness. Since the Spanish colonisation, there has been a prevalence of the Christian religion and the Charity Model of Disability that leads to the creation and maintenance of the association of *uselessness* and *less fortunate* towards people with disabilities. These associations lead to the belief that people with disabilities need help, producing a *saviour mentality* embedded in charitable activities that enhance the ableist power dynamic that benefits able bodies under the discourse of *helping to earn heaven.*

Additionally, there is a denial of the emotional impact of sight loss as an attempt to hide it from the Council to secure funding. This denial could relate to the anxiety of accepting the possibility of losing sight. A defence towards this anxiety is also manifested by the fantasy of people with blindness having "other" or "better" abilities.

At last, the othering position towards people with blindness might relate to a primitive reaction to the lack of visual cues needed for sighted people to reflect and re-construct their identity. This rejection plays an important role in excluding people with blindness and visual impairments (further discussed in section 5.6).

The following section theorises how these associations influence the grieving process of sight loss and proposes a re-conceptualisation of sight loss from a psycho-social perspective by challenging previous conceptualisations on the impact of sight loss on identity.

5.3 Challenging the impact of sight loss on identity: Re- conceptualizing sight loss from a psycho-social perspective

This research is the first one conducted from a psycho-social perspective that explores the perception of blindness and emotional support for people with sight loss in Mexico. This study is based on Dr. Thurston's research. In 2010, she used a mixed methodological approach to explore the emotional impact of sight loss, which led to the creation of the Five Stage Model of Sight Loss (Thurston et al., 2010) and the emotional support protocol that is being currently disseminated in the UK for people with this condition (section 2.2). Following in her footsteps, I am taking the first step of her research and adding the psycho-social dimension. I decided to add this dimension because I wanted to explore how the culture and cultural unconscious processes influenced the emotional impact of sight loss and the access to emotional support in rehabilitation centres for blindness.

In the Five Stage Model developed by Dr. Thurston et al. (2010), one of the premises is that people with sight loss must renounce their identity as a sighted person and re-construct a new identity as a person with blindness. The results of this study build on her research, proposing that if sight loss happens at a young age, it may not necessarily have the same impact on a person's identity, such as the case of Rolando. Furthermore, this research proposes that the social perception towards people with blindness has a critical role in the impact of sight loss on identity. Therefore, a positive environment, social support, and inclusion opportunities are crucial for the adjustment to sight loss.

Thus, through this section, I theorized about the impact of sight loss on identity by re-conceptualizing sight loss from a psycho-social perspective.

As mentioned in section 2.3.1, there is a difference between identity and self. Identity is a concept that refers to the definition of one's person in a social, collective way that is made by internalizing the culture of the society we live in (i.e. national identity). On the other hand, the self consists of our psychic configuration and how we experience the world. The self would then be a unique definition of our inner world, which is complemented by the social perspective that identity adds to it (Elliot, 2014).

Belonging to a group establishes a social identity in an individual. It creates a sense of belonging and understanding of the self, similar others (ingroup) and different others (outgroup). Additionally, it provides a path for individuals to understand their place in the group and the world. When people claim to belong and identify with a group, they tend to take on the group's attitudes, behaviours, and norms as their own. Social influence includes social and psychological phenomena whereby people often make decisions (consciously or unconsciously) based on the norms and values of their group memberships. People rely on other group members for information on how to act, feel and respond (Postmes, 2010). The group's perception influences the individual's perception, and the individual perception strengthens that of the group.

As reviewed in section 5.2, the social perception towards blindness in Mexico can be summarised as blindness being "a terrible thing", and people with blindness (the "others") are perceived as useless. Additionally, this perception could be a reflection of the unconscious positioning since the Spanish conquest, in which "the sighted" society, particularly those working at rehabilitation centres for blindness, take the role of saviours, needing people with blindness (in this case) to occupy a position of needing saving. This dyad is endorsed by the Charity Model of Disability, the prevalent model in Mexico.

The Five Stage Model of Sight Loss, designed by Thurston et al. (2010), highlights that a new identity must be re-constructed as a person with blindness to adjust to this condition (section 2.1). This premise implies the psychological process of grieving the loss of sight and renouncing the possibility of seeing and finding a new position regarding the place designated by society for people with blindness. This new place could be accepting this position or challenging the social projections to build an independent life in society.

One of the questions I asked through the interviewing process was about the participants' perceptions regarding the relationship between sight loss and identity (section 4.2.5.3). In agreement with Thurston et al.'s theory, some participants, such as Ruby and Jesus, the Medical Coordinator of the Public centre, mentioned that sight loss "has a great impact on identity" as "it is related to self-worth." Other participants, such as Andrea, the visual rehabilitator from the Charity, and Patricia, said that sight loss does not impact identity (section 4.2.5.3).

Rolando mentioned, "I feel the same way as before. I just cannot see". It seems like he did not internalize the projections of society related to *inability*. This reaction may relate to him having his family's support and academic opportunities to work his way through the social barriers and achieve a professional life (section 4.5.2). Rolando's experience is related to the results of a previous study (section 1.1.2), which highlights the relevance of family support and having a social network as protective factors that aided through the grieving process of sight loss. Rolando mentioned experiencing 1.5 months of feeling depressed after completely losing sight. Nonetheless, he did not seek emotional support. He mentioned that his family and friends supported him through the process, and it was crucial for him to have the possibility of continuing his education and activities.

This relates to the following passage in Freud's Three Essays on Sexuality (1905):

' Auntie, speak to me! I'm frightened because it's so dark'. His aunt answered him: 'What good would that do? You cannot see me'. 'That doesn't matter', replied the child, 'if anyone speaks, it gets light' (p. 224). Upon this quote, Freud concludes that the child's fear is not towards darkness but of losing a loved one.

Rolando identifies as *blind*, not as a *person with blindness,* as some other people choose to identify to show that blindness is something they *have*, but not a defining trait in their identity. Nonetheless, his actions show that blindness has not stopped him from doing what he wants to do in his life. Additionally, he uses phrases such as *I'll see you tomorrow* or *let's see* when others choose not to use the verb *see*, as they won't be *seeing tomorrow.* When asked about these phrases, he mentions that it's *just* the common language, and he can use them without it representing a problem.

Daniela, like Rolando, also lost her sight at 14. Nonetheless, her experience was very different. She mentioned feeling *"like the world was ending"* when she lost her sight. Rolando and Daniela had their family's support, but it was presented differently. For Rolando, his parents pushed him to continue studying and advocated at the school for an opportunity for him to keep going to his classes. In the case of Daniela, her mother started doing everything for her, which made her feel incapable of doing anything without her mother. Additionally, she was granted her middle school degree as an act of pity from the Director. Afterwards, she was not accepted at any regular high school (section 4.2.5.2).

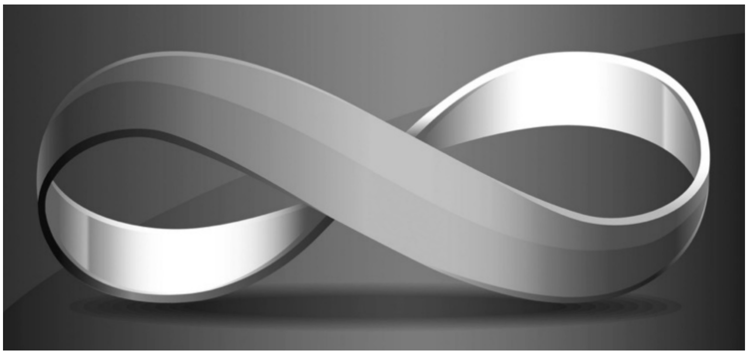
The social reactions towards Rolando from his family and school seemed to come from understanding his sight loss but not using it to define him as unable. On the contrary, they supported him and gave him tools to continue his education and develop a professional career. On the other hand, the social reactions towards Daniela were disabling. Her mother, doing things for her instead of supporting her in finding different and new ways of doing them herself, made her feel that she couldn't do anything without her. Additionally, the pitiful reaction of the school's Director to give her a diploma she didn't earn instead of finding inclusive strategies for her to achieve the academic level disabled her from continuing studying.

Although both Rolando and Daniela had different experiences and reactions towards sight loss, the fact that Rolando mentioned that sight loss didn't affect his identity leads to questioning if sight loss, when happening in childhood or adolescence, and if given the social support to continue their activities, may not necessarily cause the same impact in identity as when it occurs in adulthood.

This reflection led me to re-conceptualize my understanding of the impact of sight loss on self and identity by considering the social dimension. As mentioned previously, the research process may be an opportunity for the researcher to question themselves and reassess previously constructed assumptions (Crociani-Windland, 2009).

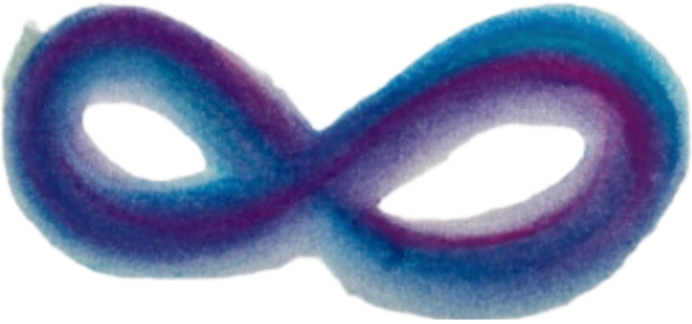
After conducting this research, I decided to use the Möbius strip to represent the psycho-social intersection I now theorize of sight loss.

The Möbius strip is a surface that is formed by attaching the ends of a strip with a half twist:



Graphical representation of a Möbius strip, by Mirek Dymitrow (2017)

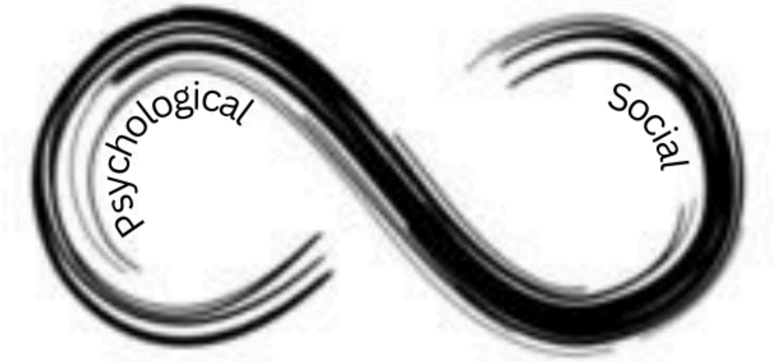
The Möbius strip is a non-orientable surface, meaning that if an object travelled one time around the strip, it would return to its starting point as its mirror image. Within the Möbius strip, it is impossible to define which way is clockwise or counterclockwise. Additionally, the Möbius strip has only one side. An object that slides one time around the surface will return to the same point on what appears to be the other side, showing that both the “inner” and “outer” sides are a single side (Pickover, 2006). This image was selected as a logo by The Association for Psycho-social Studies as a representation of the intersection between the individual and society (APS, 2023).



Logo of the Association for Psychosocial Studies logo (2023)

Psycho-social studies explore the meaning between the individual and society under the premise that it is impossible to think of one without the other (Association for Psychosocial Studies, 2023).

Following the premise of psycho-social studies, the psychological and social dimensions of sight loss are not, and cannot, be independent from each other:



After conducting this research, this is the psycho-social intersection I now theorize of sight loss.

Thurston et al. Five Stages of Sight Loss Model (2010) is based on research conducted solely with the adult population, concluding that sight loss significantly impacts identity. For blindness to be accepted, she proposes, a renounce must be made to the identity as a sighted person to reconstruct a new identity as a person with blindness. This theorization resonated with my experience with my mother, who never renounced the possibility of seeing (her identity as a sighted person) and never adjusted to blindness.

Nonetheless, this research shows that, at least for children, this may not necessarily be the case. A possible explanation is that the identity of children and young people is still developing. Therefore, when sight loss occurs at a young age, it is incorporated as an aspect of the identity being consolidated (see section 2.3.1 for further reference on identity development). Although further research is needed on the topic to determine the impact of sight loss on identity in children and young people, what seems to be critical factors are social support, a positive environment and inclusion opportunities.

These factors may also play a role in the impact of sight loss on identity for adults. As with any grieving process, what may affect identity is the meaning each person gives to sight and sight loss. This meaning, and therefore the emotional impact of sight loss, is influenced by the social perception and the position given to people with blindness within the family setting and society at large.

Hence, the social perception of blindness defines the new place a person with sight loss will have (or will have to challenge) in society. To recap: in Mexico, the social perception towards blindness is of it being something terrible that makes a person useless. Some people accept this place through the grieving process, such as those who take the economic benefits for people with disabilities but do not seek a rehabilitation process (section 4.2.3.4). Some others challenge this position, pushing through the social barriers to build another reality for people with sight loss as capable of doing everything, just differently (section 4.5.2). Furthermore, some others participate in a silence resistance by creating an informal organisation to earn an income through begging in the streets, using the Charity Model of Disability to elicit pity and a charitable reaction from sighted people. This is further explored in section 5.7.

If the person with sight loss has a positive social network and can continue having (or create) an independent and productive place in the society they live in, sight loss is less likely to become a defining trait in their identity. Blindness becomes something a person has, not something that defines the person. Moreover, even if they define themselves as "blind", such as Rolando, they don't necessarily perceive themselves as useless or inferior, as the social association indicates. On the contrary, if the person with sight loss cannot continue (or create) an independent and productive place in society, they are at risk of becoming isolated, prey to negative social and family attitudes that endorse the social idea that people with blindness are useless, sight loss is more likely to affect identity.

Given that the place allocated to people with sight loss in Mexican society is that of an inferior (in the superior-inferior dyad), useless being, the resistance to accepting sight loss might be unconsciously related to the acceptance not of blindness but of the place a person with blindness has in society. Perhaps we can think of a variation of the poem by Dylan Thomas (1951): "Rage, rage against the dying of the light". Rage, yes. Rage against the social perception of the dying of the light.

Could the social perception towards blindness be challenged and transformed from being a condition that makes a person useless to being *just* an impairment that does not have to define a person's capability or place in society? Could we create an inclusive society in which a person with sight loss could continue living doing the same things as before, just differently? Would, then, the grieving process of sight loss be different? Less challenging, perhaps? Less scary?

I want to believe it would.

5.4 Critical reflections on the methodology

As mentioned before, this is the first research that explores the perception of sight loss and emotional support in Mexico in Psycho-social Studies.

The methods I decided to use were the Free Association Narrative Interview Method (FANI) for the staff members and the Biographical Narrative Interview Method (BNIM) for the users of the centres (section 3.3.1).

I selected the FANI method as it provided a free-associative narrative approach that would allow the participant to explore the subject at hand freely (Hollway and Jefferson, 2008). Additionally, FANI is useful for exploring identification processes, a helpful characteristic when exploring the associations that may arise when working at a rehabilitation centre for blindness when identifying themselves as a person who could become a person with sight loss.

The BNIM was selected as it is a methodology that explores lived experiences through a narrative that facilitates the expression of the inner world and the interaction with the cultural and social world (Peta, Wengraf and McKenzie, 2017). With the users, I was particularly interested in exploring not only their experience of sight loss and their perceptions towards blindness but how the culture influenced that experience and perceptions.

In the second progression exam of the PhD programme, the examiner asked me why I hadn't used ethnography. As ethnography is a method in which the researcher immerses themselves in the community to explore complex organisations (Atkinson, 2014), my examiner mentioned that this method could have given me more information on the social perception towards blindness in rehabilitation centres by exploring this perception from the inside.

Two obstacles disqualified ethnography as the selected methodology for this study. The first one is that by the time I needed to conduct the interviews, the rehabilitation centres were either closed (the charity centre) or did not allow external visitors (public centre) due to the covid-19 pandemic (see chapter 3 for further reference). Hence, there was no possibility of conducting an ethnography.

Additionally, as this is the first research conducted in this discipline that explores the perception of blindness, I felt more comfortable using a more structured way that would allow me to map where we are as a society in a more exploratory way. Nonetheless, there are things I would have done differently or, perhaps, would now do differently.

When I designed the eliciting questions, I aimed to explore the perception of blindness and emotional support services provided at the centres (if any). Nonetheless, reflecting on the process, I realise now my questions were biased towards understanding the perception of sight loss- in relation to- emotional support services (i.e. what do you think about emotional support for people going through sight loss?) instead of exploring the perception of blindness itself to elicit both the psychological and social associations.

There was one question no participant understood: Can you tell me more about sight loss and identity?" This question came after "How do you think a person with sight loss perceives themselves?" Perhaps none of them had reflected upon the possible impact of sight loss on identity. However, I believe it may have been better to ask open-ended questions that progressively lead to that one, i.e. "How would you define identity?" "Do you think there might be a relationship between sight loss and identity?"

Nonetheless, the fact that no one could directly answer the question is a finding in itself. Sighted people working at the rehabilitation centres perceive people with sight loss with pity and as “useless”, but there is no recognised link between that association and how it might affect identity. Additionally, there is a contradictory way of thinking about sight loss when it comes to providing rehabilitation services, which aim to make the person with blindness independent to be able to have a place in society (or at least that’s the centres’ official discourse) and the assumption that sight loss made the whole person less capable and worthy of that exact place.

The interview process

Researching is an intimate process in which at least two people come together to share thoughts and feelings (Lahman, 2017). During the interview process, I focused on maintaining a transitional space (Winnicott, 1971) that allowed for the co-creation of meaning. I held on to Jessica Benjamin’s concept of thirdness: “the process of creating thirdness, that is, in how we build relational systems and how we develop the intersubjective capacities for such co-creation” (Benjamin, 2004, p. 4). Furthermore, she mentions that

> We might say that the third is that to which we surrender, and thirdness is the intersubjective mental space that facilitates or results from surrender. In my thinking, the term surrender refers to a certain letting go of the self, and thus also implies the ability to take in the other’s point of view or reality. Thus, surrender refers us to recognition—being able to sustain connectedness to the other’s mind while accepting his separateness and difference. Surrender implies freedom from any intent to control or coerce (Benjamin, 2004, p. 8.).

The purposeful creating of thirdness along with the constant use of reflexivity to recognise my own unconscious defences (Hollway and Jefferson, 2013) led me to reflect on the transference and countertransference displacements that took place during the interviews and what those interactions might say about the culture.

Transference is the displacement of the affect from one representation to another. More specifically, the transference of the unconscious representations from a person previously known by the patient to the analyst. The display of that transference will provide information about the psychic reality and unconscious struggles of the patient, and through the interpretations of the analyst to make those reproductions conscious, the resolution of the transference would lead to the analytic cure (see chapter 4 for comments on the transferential positions during the interviews). Countertransference, on the other hand, refers to the unconscious reactions from the analyst towards the analysand. These reactions can be produced either by the patient's transference or by the analyst's own feelings projected into the analytic setting (Laplanche & Pontalis, 2004, p.84).

Transference and countertransference are also manifested in the research process:

> Both researcher and researched are anxious, defended subjects whose mental boundaries are porous where unconscious material is concerned. This means that both will be subject to projections and introjections of ideas and feelings from the other person. It also means that the impression that we have about each other is not derived simply from the 'real' relationship but that what we say and do in the interaction will be mediated by internal fantasies that derive from our histories of significant relationships (Hollway & Jefferson, 2013, p. 42).

My relationship with the charity started when I was a child. When my mother lost her sight, the charity didn't have rehabilitation services, but through one of my mother's friends, they gave us tools to learn braille. Since then, I have recognised this charity as the place where they provide medical support for people with sight loss and later developed rehabilitation services, but didn't have the tools to help my mother cope with blindness. With that reference in mind, I came back as an undergraduate researcher to explore the grieving process of sight loss. However, the research results were insufficient for the centre to address the gap in providing emotional support for people with sight loss (see section 1.2 for further reference).

This time, coming back as a doctoral student from an international university determines to some extent my positioning within the research and how the participants may have perceived me, given Mexico's history and its links to the valuing of international versus local knowledge and culture. In Mexico, it's common for people to privilege anything international over local. The colloquial phrase is that *Mexico es malinchista.* Malintzin, or *Malinche,* was an indigenous woman given to Hernán Cortés along with 19 other women, gold and blankets after they won the battle against Tabasco in 1519 and who became the only translator of Cortés. Along with her duties as a translator, she provided valuable information about the Mexica empire, their internal weaknesses, their relationship with other towns and ethnicities and the discontent of some indigenous settlements because of the tax imposition of the Mexicas. That information was key for the Spanish to make strategic alliances that led to the conquest's success (Real Academia de la Historia, 2023). La Malinche is considered a traitor, even though she was given as a prize to the Spanish for winning the battle against Tabasco. In 1922, Cortés had an illegitimate son with Malintzin and in 1925 he ordered her to marry one of his veteran captains. She died in 1926, shortly after having a daughter with him (Real Academia de la Historia, 2023). This is a historical example of the patriarchal order and objectification of women that still prevails today in Mexico. In this country, it's common to find verbalisations and actions from both men and women exalting masculinity. Attitudes and activities that are defined as masculine, including harassment and aggression, are praised and taught within families. As a result, hereditary education normalises the gender inequalities that have seen women as objects throughout history. As is the case with sight loss (or any disability), the social perception of sexism and the position given to men and women within the family setting and society at large plays a crucial role in the building of that same society.

Mexico es malinchista means that Mexicans privilege anything international (from the Global North) over national. This can be related to the myth of the conquest (Hernandez de Tubert, 2021) and the fantasy that the Global North is a superior race, the "civilised" race, that comes to teach and save us.

My skin is white, and my last names are Thompson (an English last name) and García (a Spanish one). I graduated from Bachelor's and Master's degrees from one of the private, most prestigious universities in the city. I approached the centres as a doctoral researcher from an international university. According to the Organisation of Economic Co-operation and Development (2019), 0.1% of the Mexican population have a PhD. Additionally, the doctoral programme is from an international university in England (the Global North), hence perceived as "better" than the Mexican (or Global South) universities. All those identifiers made me appear as a person belonging to a high class. Additionally, I trained as a counsellor for Sight Loss at the RNIB. I was aware that during this research, I was embodying the coloniser who brought knowledge from the Global North—the saviour.

My entrance to the charity centre was through an ophthalmologist who has the only low-vision clinic in the city. She has an agreement with the charity: the patients that arrive at the charity with low vision are sent to her, and she treats them for free, and her patients of low vision who lose sight are referred to the charity. She sometimes refers patients losing their sight to me as she knows I trained as a counsellor for sight loss. This ophthalmologist talked with Ruby about me and asked her if I could conduct the interviews at the charity. Hence, when I talked with Ruby, she knew about the research and was very welcoming in helping me set up the interviews. At first, I thought she was doing it as a favour to the ophthalmologist. Later, when I started addressing the gap to implement emotional support in the charity by training the hired psychologist, the psychologist told me Ruby wanted to keep me around because it provided internationality to the charity. On the one hand, that made me feel sad because it seemed that the interest of the charity was to use me "to have an international status," but, on the other hand, if the internationality they valued could provide a way to enter and be validated in the institution, I could use that to bridge the gap and try to address the needs and obstacles to implement emotional support for people with sight loss.

At the beginning of the interview with Carlos, he asked me some questions regarding my credentials and the doctoral programme. At first, I thought there were clarifying questions about the research, but reflecting on them, I believe they were clarifying questions about my social status. As mentioned above, my alma mater, studying internationally, and my last name placed me in the imaginary as someone that comes from money. Perhaps this was a way to evaluate if I was "at his level" within the socio-economic status. Throughout the interview, he seemed to be wanting me to know he was "a good Christian" who was "helping because he was grateful for his blessings" and "wanted to earn heaven" by doing so. At the end of the interview, he tried to convince me to work as a volunteer psychologist at the centre by reiterating that "we have to help and give back some of the blessings that were given to us" and "it would be vulgar to help and ask something in return."

His interview was the one in which I struggled the most to hold a space of connection while respecting and accepting our differences in perceptions. He was positioned entirely in the Charity Model of Disability, placing himself as a saviour and not willing to question that position. One of the comments that most infuriated me was when he "told his secretary to buy the candy that children with blindness sell in front of his office". This was, he said, his way of "helping them in their job and with their efforts." It infuriated me that he believed he was helping those children earn some money instead of addressing the real problem: Why were children (with or without blindness) selling candy on the street?

Reflecting on my anger, I realised his interviews took me back to when I was a child living with my mother. My maternal family is Catholic, and without knowing, they enacted aspects of the Charity Model of Disability throughout my mother's sickness and sight loss. They tried to understand her medical condition through the lens of religion, telling her she was special as she was "earning heaven by suffering purgatory on earth." My mother held on to this idea as I believed it gave meaning to her suffering. Neither my mother nor I could work; I was a child and my mother, besides having further health complications due to diabetes, couldn’t find a job as there were no work opportunities for people with disabilities. Hence we lived out of the charity my family gave to us. Sometimes, none of them wanted to help us economically, saying it "wasn't their responsibility". I would hear my mother beg her siblings for money on the phone until one of them agreed to help us. They also said it was a mistake that my mother had me. However, in the end, I was "an angel that god sent to take care of her." I believed they said this to avoid the responsibility of caring for her (and for me) and making me willingly -voluntarily- take care of my mother, as it was the purpose god had given to my life (Thompson, 2022).

What I found most infuriating about the relationship between Carlos and my family is not their perception of the Charity Model of Disability but the absolute certainty that that is the only way disability could be seen. I felt the same despair I felt with my family by not finding a space to challenge this perception. With the use of reflexivity, I was aware of that anger and prevented it from being enacted in the interviews. Nonetheless, without being conscious of it, I did influence those interviews. In the next council meeting, this council member mentioned the relevance of hiring a psychologist instead of having a volunteer. This impact is expanded on in the next section.

Marycarmen, the Director of Quality of Rehabilitation Services, and Alexa, the Director of Inclusion Services of the Public Centre, treated me as an equal. This may be related to the recognition of women working hard in our professional careers. These were the most pleasant interviews for me. Both were aware of the obstacles of our society and the centre. During the interviews, we could openly talk about our perception of the social barriers and the efforts in which we were actively trying to address those barriers. They were also open about their change in perspective before and after they started working at the rehabilitation centre, acknowledging they, too, used to see people with visual impairments with pity, but now they were trying to change that perspective in our society.

On the other hand, Miguel, the Medical Coordinator, and Alex, the Rehabilitation Coordinator, enacted the patriarchy that is lived in Mexico every day. They mentioned that "working with disability takes vocation" and that "for a woman that is economically sustained by her husband is easy, but for a man that has to provide for a family, it's not." Although they expressed pride in being men holding on to a position for vocation regardless of the difficulties of providing for a family, I believe this comment was also made to clarify a distinction between "them" and me. As if wanting to say that I could dedicate to this because (in their imagination) I had a husband that supported me economically. However, they did it regardless of having to provide for a family. As mentioned previously, this comment elicited anger in me because it shed light over the patriarchal system that still predominates in the Mexican culture and portrays the traditional gender roles. Although I'm an active member of the feminist movement in Mexico, which prompted me to challenge this perspective, I decided not to address it as it was not the subject of the interview.

Nonetheless, my silence made me feel that I was betraying my sorority, as it is documented that the silence and submissiveness of Latin-American women contribute to the maintenance of patriarchy and allows men to continue exercising their role as "superior" (Martínez & Díaz, 2021). As with the Charity Model of Disability, the patriarchal system that predominates in Mexico affects me directly and elicits emotions. While being aware of my emotional reactions, I remained as neutral as possible in both cases. As Jessica Benjamin mentioned, I surrendered my beliefs to sustain the connection with the other, accepting their separateness and differences, and renouncing challenging or attempting to control their perception (Benjamin, 2004).

Patricia, the Psychologist from the Charity, was giving what seemed to be answers with the least words possible. In those replies, she was trying to engage with me to avoid answering, alleging that "I knew", and thus it was unnecessary to reply. For example, when I asked her how she treated people with sight loss, she replied, "There isn't a specific way. You know, you're a therapist, you have to establish an alliance, and that's it." Hers was the shortest interview, and she didn't reply to my request for a second interview. Given that Ruby, who positioned me as having this "international value", was the one that requested the interviews, I believed she might've felt challenged in her work by my presence and by the interview.

On the other hand, Mariana, the psychologist from the Public centre, engaged in a conversation with me throughout the interview about her experiences of the emotional process of people with sight loss and was open about the gaps in the psychology area of the centre, i.e. theoretical knowledge and clinical skill to work with people with sight loss. At the end of the interview, she asked me to train her and the other two psychologists in the area.

Andrea and Ana, the Visual Rehabilitators from the charity and the public centre, respectively, were open to sharing their experiences with their students. Besides the interview, Andrea let me watch one of her classes with a seven-year-old boy. She taught him braille and the use of the Cranmer abacus so he could use those resources at school. She introduced me to the boy as a visitor, and I engaged with him in the class (and learned to use the Cranmer abacus). After the class, we talked about the differences between a family that has worked through the grieving process of their child having a visual impairment and thus letting them become independent (as was the case of this boy) and other families that were overprotective and how important it is for families to have a space to work through their own grieving process. I was grateful to her for sharing with me not just the verbal information but the experience of a class (a tiny bit of ethnography) and for engaging with me in the gaps that the implementation of the emotional support services should consider addressing.

A significant detail appeared in the interview with Ana. Halfway through the interview, she stood up to close the door and said, "better this way". I believe that gesture meant she felt enough confidence to talk with me (and not so much in her institution). What she disclosed afterwards was that the centre said all patients with a chronic condition were supposed to be referred to have a session in the psychology area. However, when the patients arrived with her, they haven't been sent to psychology. She felt confident enough to tell me something wasn't working at the referral system of the centre.

That gap was created by David, the ophthalmologist of the public centre. All patients with visual impairments were referred to him to confirm their diagnosis, and he designed their rehabilitation plan. At the beginning of his interview, he seemed discouraged. He mentioned he was disappointed that it seemed that the patients went to the centre to get diagnosed with a disability and get their discount card but didn't want to go through the rehabilitation plan he designed for them. Thus, he stopped referring the patients to the psychology area. Through the questions, he reflected on this and appeared to be encouraged to send the patient to the best possible rehabilitation plan for them, regardless of if the patient would or wouldn't go.

The interview with Rolando was difficult for me. I was interviewing him as a staff member and addressing his experience with sight loss. That double role represented a challenge for me as I caught myself trying to find the right way to address both him and the questions in a politically correct language to avoid conflict. He didn't seem to have any conflict answering my questions but didn't elaborate further. It wasn't until later, when I provided the training in the Maccia protocol to the instructors (see the next section -5.5- for further reference), that Rolando and I started to get along. I learned he identified as *blind* and made jokes about his blindness. He rejected the position the centre gives him as a role model for students to push through the barriers by telling them that "if he could do it, everyone else can". He understood the barriers from a Social Disability Model and used his job to find the best way for each individual student to deal with those barriers. There was a significant moment when, after the module in which he discussed the relationship between identity and sight, he asked to talk with me. He told me he was expecting a baby with his wife, who also lost her sight. The gynaecologist told them there was a good chance the baby had no visual impairments. He asked me if I thought it could be important for them to enrol the baby in a nursery school at an early age so they could get the visual stimuli they couldn't provide. This question was very meaningful to me because it represented his trust in talking with me about a personal struggle in relation to what we discussed earlier in the module.

Both users shared a positive experience from the centre they were going to. Daniela, a student from the charity, mentioned that the courses helped her understand that her life wasn't over. Claudia, Juan's mother, talked about Ana's dedication in Juan's sessions. I believe they might've been trying to protect the space they have to get rehabilitation services. Perhaps they didn't feel enough confidence to talk about the challenges they face through the system. Rather than discussing the rehabilitation centre, Claudia expanded on her experience of the challenges of finding Juan access to education. She mentioned that private schools rejected him, so she turned to a public school that let him enrol. She's aware that the activities he must do are easier than the ones his classmates do. "I don't expect a miracle; I'm just asking for a chance," she mentioned. It seemed like she was trying for me to see the gaps in the educational system for people with visual impairments through the interview. Those gaps are further addressed in section 5.6.

One of the complexities of this research was to hold the double role of researcher and psychoanalyst in my mind. As mentioned in section 3.3, because of my training as a psychoanalyst and free-associative psychoanalytic technique that the methods draw upon, a challenge I had was to constantly be aware of not turning the interviews into psychoanalytic sessions. Nonetheless, it was also hard to hold in my heart a third role as a family member of a person with sight loss.

Countertransferencially, I relived my own experiences as a daughter of a mother with sight loss through the interviews. I would feel angry and disillusioned when an ableist comment was made, such as referring to people with blindness with pity or as "incapable". On the contrary, when a comment was made concerning the Social Model of Disability, such as Ruby, Rolando, Marycarmen and Alexa mentioning the importance of recognising the social barriers, I would feel hopeful.

Additionally, whilst interviewing the users of the rehabilitation centres with the BNIM, I remembered my struggles through the medical system trying to get the resources my mother needed. I felt identified with the users, and I struggled to avoid siding with them to find answers to their problems or ways to improve the services in the centres. My emotional reactions called me into action. Hence, I struggled to empathise while remaining in a "neutral" position to explore what the interviewee shared with me. Ultimately, I couldn't sit with the information and do nothing. As an effect of this research, I founded an association that provides training for psychologists and staff working with people with blindness and visual impairments and develops projects promoting inclusion services (this is further expanded in the next section).

In conclusion, I believe the FANI and BNIM methods were the right place to start because they allowed me to explore the conscious and unconscious perceptions towards blindness. Most significantly, the FANI method, because of its narrative approach and the psychoanalytic principle of free association (Hollway & Jefferson, 2008), allowed me to shed light on the defences mobilised by the participants when exploring their experience working with people with blindness.

Another complexity of the research was working within two languages and two cultures. The interviews and one of the data panels (with Mexican Researchers and Psychologists) were made in Spanish. For the second data panel (with psycho-social researchers from the University of the West of England), I had to translate the interviews that would be analysed. Luckily, my Director of Studies is Italian and Spanish speaking descent, so she speaks Spanish. Hence, I didn't have to translate all the interviews.

Nonetheless, writing the analysis, findings and discussion required working through not just the verbal translation from one language to another but also bridging the gap between cultures.

One of the difficulties for me in bridging this gap was that I was applying the knowledge I've gathered both from the doctoral studies at the University of the West of England and training as a counsellor for sight loss at the Royal National Institute for the Blind (RNIB) to the Mexican population, which has a very different cultural context. I was aware I needed to be careful not to impose England's reality (as a coloniser would do) but use that reality as a frame of reference for the emotional support that could be implemented. With this frame of reference, I actively listened to the participants' personal and cultural experiences and perceptions, differentiating the aspects from England that could be applied to the Mexican population from those that had to be adapted.

Now that the "mapping" of the available information is done, I believe the next step would be an ethnographic study—ethnography focuses on exploring the complex organisations of everyday life. Nonetheless, the fieldwork done via ethnography requires the researcher to bring ideas *into* the field and try to get ideas *from* it. A framework is needed beforehand to support the emerging ideas that would guide the fieldwork further (Atkinson, 2014). I believe this research can provide that framework for future studies of the social associations towards blindness in Mexico.

Questioning the current perceptions towards blindness in the rehabilitation centres for blindness in Mexico led to the possibility of addressing the gap to incorporate emotional support for people with sight loss at the rehabilitation centres. The following section (5.5) reflects on this process.

5.5 The impact of this research in questioning the current perceptions towards blindness in the rehabilitation centres for blindness in Mexico.

Through this study, I wanted to understand why the charity centre was telling me that emotional support wasn't important for someone to adjust to sight loss to understand the needs and obstacles to address this gap. This study was meant not just to understand but to lead me to the knowledge that I needed to act in addressing this gap. Perhaps I didn't know consciously what the path to it might be but, as Machado (1912) says, "caminante no hay camino, se hace camino al andar" *(traveller, there is no path, the path is made by walking)*. I made the path by walking the journey of the PhD.

As mentioned in the previous section, the interview that most affected me emotionally was the one with Carlos. He was fully positioned in the Charity Model of Disability, taking the role of saviour toward people with sight loss and verbally stating this was “his way of earning heaven” (section 4.2.1.1). As I conducted the interviews with him, I tried to be very careful with my words and direct my comments towards exploring the research questions and not towards an interpretation or confronting his views. His were the most challenging interviews of the research.

After I conducted both interviews with him, Ruby called me, saying she “didn’t know what I said to Carlos, but they had decided in the council meeting to hire a psychologist.” Without me actively trying to influence in any way, I had. As the Hawthorne effect states, you can’t look at something without altering it (Wickstom & Bendix, 2000).

In one of my travels to England for the PhD, I had written an email to the CEO of the RNIB to tell him that I was trying to make a change for people with blindness and visual impairments in Mexico, and I wanted to learn from the RNIB. He didn’t reply, but his assistant did, and she re-directed me to the Head of Services, with whom I met. He offered me all the support and resources I needed to learn from the RNIB and the possibility of bringing that knowledge back to Mexico. I was directed to the emotional support services, where they told me they had a course for therapists to become counsellors for sight loss, and I could take it. I enrolled immediately. To my surprise, one of the instructors was Dr. Thurston. After I finished the course, I asked her for a meeting to introduce myself and tell her my PhD research was based on her work, replicating the research she had done 12 years earlier in the UK in Mexico, and adding the psycho-social dimension to it. Since then, she has become a consultant on this study and a mentor in my path of building access to emotional support for people with sight loss in Mexico.

Through this research, along with Dr. Thurston, I became not just a Doctoral researcher and consultant but also an academic actively contributing to the improvement of emotional support services in this area of Mexico. Working together, we adapted the emotional support model used at the RNIB and Retina UK for the Mexican population.

We then developed a clinical training for psychologists in my country. One of the main challenges was that in the training offered by the RNIB to clinical psychologists, it is assumed they already know certain concepts, such as the definition of ableism and the different models of disability. In contrast, in Mexico most people don't know what these terms means. Therefore, we designed a broader course that includes the epidemiological, social, and clinical theoretical foundations as well as clinical practical activities. Additionally, in the social We called it *Protocolo Maccia: Acompañamiento Terapeutico en la Pérdida Visual (Maccia protocol: Therapeutic Companionship in Sight Loss).* This protocol is included in appendix 9.6.1. *Maccia* is a variation of my mother's name, Martha. The theoretical, non-clinical part of this training is also offered to health professionals such as ophthalmologists, visual rehabilitators, social workers, staff from rehabilitation centres, teachers, family members and everyone who wishes to learn.

To have a platform to deliver this training, I developed an association also named *Maccia*. This platform is dedicated to training professionals and developing inclusion projects for people with sight loss and visual impairments.

Both Ruby and Carlos knew about my training as a Counsellor for sight loss at the RNIB, as I mentioned it when asking for permission to conduct the interviews. Also, I was transparent about building the protocol for emotional support for people with sight loss, which happened as a parallel process at the time of the interviews. After the council approved hiring a psychologist, Ruby asked me to train them and help build the psychology area. The first time I taught the protocol was to this newly hired

Psychologist and the Coordinator of the Educational Area. It was endorsed by Dr. Thurston, who connected in one of the sessions to greet the students and signed the certificates with me. When that course finished, they asked me to teach the visual rehabilitators working at the Charity. They became the second generation of this training.

When my mother lost her sight, there wasn't emotional support available either for her to process her loss and adjust to blindness or for me to process that my mother wouldn't be able to see me anymore. The nine years that followed her sight loss were filled with pain, frustration and sadness for us. Not everything was negative, we had good moments and laughs, but there was always the shadow of blindness around us. After her death, I knew I needed to change my experience, to transform that pain. To use my woundedness to heal (Zerubavel & O'Dougherty, 2012). After 25 years of research and active work, I was able to transform that experience, if not for me, at least for others, by providing training for people working at the rehabilitation centre who couldn't help my mother and me.

Dr. Thurston et al.'s model (2010) suggests that each person has specific needs in terms of emotional support. Not everyone would need this support at the same moment, as there are periods when living with blindness could be more challenging. From Rolando's experience, we could say that perhaps not everyone necessarily needs professional emotional support living with sight loss (section 5.3). Nonetheless, it should be available to whoever needs or wants it. This research was the venue to make this happen.

Academic activism refers to the engagement of academics to promote social change. There are at least four ways in which academia can be a place for activism: producing knowledge to inform change, conducting research that involves social change, teaching progressive strategies, and using institutional power relations to promote change (Flood, Martin & Dreher, 2013). There has been an increase in calls to academia to step beyond the traditional teaching roles and become activists to influence policy. However, there's still limited engagement from academics. One of the reasons is that some academics believe they have to stay "detached" and "neutral" for fear of losing scientific credibility. Another challenge for academic activism is the institutional barriers, such as high competitiveness within the academic environment, where promotions or job opportunities privilege high-impact publications instead of real-world impact (Gardner et al., 2021).

Through this research, I became an academic activist by passively influencing the council member of the charity through the interview process and thus opening the possibility of consolidating a protocol to offer emotional support for people with sight loss. It fills me with excitement that because of this study, I'm impacting real people. I believe this is the goal of academia, to create social improvement with our research.

Once the gap in incorporating emotional support for people with sight loss started being addressed at the rehabilitation centres (section 4.4) and people going through this process had access to the tools to adjust physically and emotionally to blindness, my next question was, "adapt where?". Even if a person with sight loss is fully adjusted physically and emotionally to blindness, inclusion is limited for people with impairments in Mexico. Moved by this question and my desire to understand the obstacles in terms of inclusion for people with blindness and visual impairments, I took a step forward in this research and interviewed the Director of Inclusion Services in the public centre. The following section theorises the results gathered in relation to inclusion of people with blindness and visual impairments (section 4.5) through the lens of Disability Studies.

5.6 The extra mile: inclusion in Mexico for people with blindness and visual impairments through the lens of Critical Disability Studies

To explore the inclusion opportunities for people with blindness and visual impairments in Mexico, I decided to take a further step and add a question regarding inclusion in the second interview of the FANI method used with the members of staff at the rehabilitation centres: *Can you tell me about the inclusion services provided by the centre?* Additionally, I scheduled an interview with Alexa, the Director of Inclusion of the public centre, to explore the inclusion services offered by this area.

Three things caught my attention when exploring the inclusion services in the rehabilitation centres (see section 4.5 for further reference). First, at both rehabilitation centres, there seemed to be a recognition of the social barriers (i.e. limited accessible infrastructure, lack of access to education and resistance of companies to hire people with blindness or visual impairments), but not much active focus on bettering social conditions by trying to remove the barriers. Perhaps, as Meekosha (2010) mentions, removing the barriers would mean losing visual impairments as a social product and the gain the centres might have from the current dynamic.

Second, the charity centre provides academic follow-up at elementary and middle school to the children taking rehabilitation courses at the centre. The instructor at the centre meets with the schoolteachers to ensure the child is getting what they need to continue their studies. Nonetheless, once they finish elementary school, there isn't academic follow-up for high school and higher education. Concerning the previous idea, it is expected that by the age the child enters high school (15 years old), they can tell the teachers what they need to be able to continue their studies instead of ensuring that academic activities are inclusive at every level. Additionally, Rolando shared that a problem they have with teachers at elementary and middle school is that they adjust the activities for children with blindness to make them *easier* rather than accessible (i.e., instead of having to do ten math problems, they must do the two easiest ones). Therefore, when the child even tries to enter high school, they cannot reach the academic entry level. This reinforces the self-perception of being less intelligent rather than the academic barrier placed upon them because of their physical impairment. Alexa also mentioned the resistance of teachers and academics at all levels to include students with blindness and visual impairments because “they don’t know how to treat them.”

This relates to a study conducted in 2018 by Ravenscroft et al., that explored the attitudes of elementary school teachers in Turkey towards the inclusion of visually impaired children in regular schools. For this purpose, they used a questionnaire adapted from the Facilitating Inclusive Education and Supporting the Transition Agenda projects. The first part of the questionnaire registered the teacher’s individual and demographic information (experience, age, school, training, etc.). The second part explored the teacher’s attitudes towards visually impaired children through 14 statements. Results showed that teachers hold positive attitudes towards inclusion, but feel unprepared to teach visually impaired children. The conclusion of this research is the need to train teachers to facilitate inclusion for visually impaired children.

Although further studies are needed, based on what Alexa was commenting, this appears to also be the case in Mexico. Sadly, even when the government knows about this lack of training, resources are not allocated to provide teachers with the knowledge and tools to facilitate inclusion.

The public centre has an inclusion area where people with all disabilities can take tests and get a profile linked with job openings (section 4.5.3). It got my attention that the tests for people with visual impairments evaluated only manual skills. Of course, if higher education is not accessible, people with visual impairments lack the educational skills to aim for anything higher than a manual job at a factory, often paid at minimum wage.

Ableism, as mentioned in section 2.4.4, is a series of beliefs, processes and practices that produce a particular body and self-projected image as perfect. Ableism entails a justification for having better rights or higher status. The Critical Disability Studies movement (Loja et al., 2012) fights ableist normalisation. It seeks to legitimate human variation, proposing that humans are valuable and capable regardless of their bodily characteristics (gender, skin colour, impairments, etc.). Meekosha (2010) mentions that this movement has to be re-formulated to include power relationships related to colonialism.

Interestingly, the base for Disability Studies in the South was initiated by Mexico, moving people with disabilities to introduce the United Nations Conventions on the Rights of Persons with Disabilities (Meekosha, 2010). Nonetheless, although there are supposed to be laws protecting the inclusion of people with disabilities, marginalisation in this country is still predominant.

In 2021 Oviedo-Cáceres et al. conducted a research that explored the meanings of social inclusion of people with visual impairments in four cities in Colombia through semi-structured interviews and analysed the data through a thematic analysis. One of the emerging categories was that the imaginary of society, meaning the ideas that sighted people have of people with visual impairments, influences inclusion opportunities.

As stated in section 5.2, the Charity Model of Disability is prevalent in Mexico. Based on this model, people with blindness are considered useless and incapable, in an inferior position. This perception directly affects access to higher education and, therefore, well-payed jobs as people with blindness are perceived as *not worthy* of the same education or jobs as *sighted* people. This exclusion is not limited to education and jobs but also extends to social events and sports. As mentioned in section 5.2, it’s common that people with disabilities in this country are not just oppressed by their impairment but suffer a double oppression at the intersection of impairment and class.

This rejection can also be related to the othering position in which there is a resistance to relate as a human being with people with blindness as it requires to be able to withstand knowing that anyone can lose sight. Another explanation for this rejection is that it could entail a reaction from sighted people to feeling rejected by people with blindness, as they cannot provide a visual reflection for sighted people to find themselves (see section 5.3 for further reference).

Challenging the imaginary of Mexican society towards people with visual impairments: an inclusive climbing programme

To challenge the imaginary of Mexican society towards people with visual impairments, we developed a programme of inclusive climbing. I'm a climber myself, and it caught my attention that I had never seen people with disabilities either at the gym or on the mountain. Consistent with several studies, children and adolescents with disabilities are less likely to participate in exercise and physical activity, and they're more likely to be inactive as adults (Qasim et al., 2014). In Mexico, the limited participation of people with disabilities in sports is mainly related to social barriers.

The benefits of physical activity not only in physical health but also its impact on psychological and social aspects have been extensively established in the literature. The most common psychological aspect that has been demonstrated to improve with physical activity is self-esteem. Self-esteem is critical since it defines self-worth and good feelings about the self, representing the best indicator of well-being (Qasim et al., 2014). As mentioned in section 1.3.2, self-esteem, along with depression and anxiety, is considered to be an aspect that is commonly present when sight loss occurs.

Climbing has proven to have a positive impact on self-efficacy. A study conducted by Kratzer et al. (2021) explored the effect of bouldering (a type of climbing that involves short problems in walls that are from four to six meters tall -representing big rocks outdoors- and the climbing is done without a harness) on perceived self-efficacy in people with depression in comparison with a home-based physical exercise programme and a cognitive behavioural group therapy (CBT). Depression was assessed with the PHQ-9 and MADRS, and self-efficacy was assessed at baseline and after ten weeks with GSE. Participants of the bouldering programme showed a significantly more significant increase in perceived self-efficacy compared with the home-based physical exercise programme. Additionally, no differences were found between participants in the bouldering programme and the CBT group regarding perceived self-efficacy. These results show that bouldering therapy has more impact on self-efficacy than physical exercise alone. Furthermore, this study indicates that bouldering therapy is comparable to CBT in enhancing perceived self-efficacy, which suggests this activity might be a good addition to treating depression.

I started researching para-climbing and learned that there are several categories: visual impairments, neurological/physical disability, upper extremity amputee, lower extremity amputee and seated (International Federation of Sport Climbing, 2023). I then started looking for para-climbers in Mexico. I found only two para-climbers in the country, one who doesn't have an arm below the elbow and another with an impairment in her legs. There are no para-climbers with visual impairments in Mexico that I could locate.

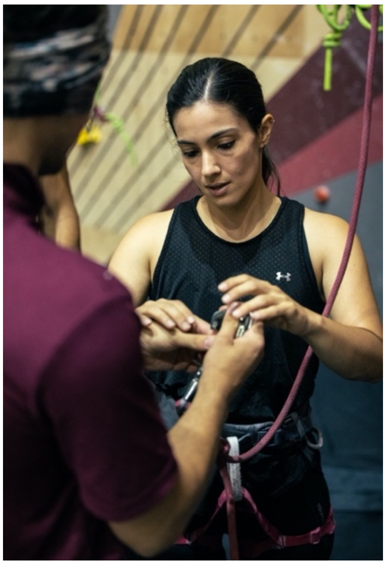
Research about the effect of physical activity on the psychological aspects of people with visual impairments is scarce. To the best of my knowledge, there aren't studies yet that evaluate the psychological effects of climbing in people with visual impairments. Nonetheless, a study was conducted by Qasim, Ravenscroft, & Sproule (2014) in which they investigated the effect of a 10-week martial arts programme on self-esteem in 5 young adults with visual impairments using the Exercise Self-Efficacy Scale (EXCE), the Physical self-description questionnaire (PSQD), the Self-Perception

Profile for College Students (SPPCS) and social validation questions. The results show that practising karate may improve EXSE (self-efficacy, self-description, and self-perception) in young adults with visual impairments. Three participants improved EXSE during and immediately after the 10-week programme; the other two participants had a high EXSE baseline, so they reported no change after the programme.

Two participants mentioned that they were not satisfied with the programme because they wanted more sessions and would like more people to be involved. This experience shows a clear example of how practising physical activity can lead to motivation and socialisation. Other participants mentioned feeling happy about trying new skills. A participant stated that they used some of the skills they learned in the programme in real life, such as the relaxation technique (Qasim et al., 2014). This resonated with my experience with climbing.

I talked with the para-climbers I had located in Mexico. They told me the primary problem is that climbing gyms are not adapted for people with disabilities, i.e. the only way to get through the gym was through stairs, the restrooms weren't big enough to fit a wheelchair and the setting of the routes was not made thinking of people without a limb.

Listening to their experience, we started developing a project to make climbing an inclusive sport for people with disabilities in Mexico. We partnered with a company that produces chalk named Monkey Hands. With their sponsorship, we started by training the staff at the gyms. We created awareness of the Social Model of Disability, the social barriers faced by people with impairments in Mexico, and how to welcome people with disabilities to the climbing community. We also had an experiential workshop in which they simulated climbing and belaying with different impairments so that they experienced that it was possible and then we worked on how to teach people with impairments the basic principles so they could try climbing.



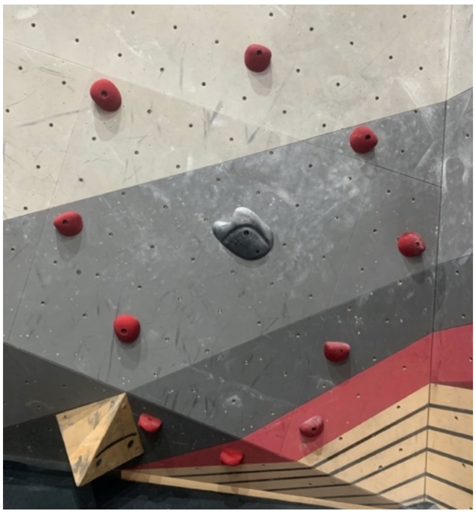
A staff member learning how to use a belay device without sight

A staff member trying climbing blindfolded

Both owners of the climbing gym took the training. Interestingly, when asked about their thoughts of people with disabilities coming to the gym, they mentioned they had never thought about that possibility, and hence the reason they didn't make the infrastructural adaptations or seek training for their staff, but they were open to making them and though it was an essential part of being inclusive as a community. It seems like they were not consciously excluding people with disabilities; they were not thinking about them, which is an exclusion in its way.

After training the staff, our first event consisted in taking children with visual impairments who were actively taking courses at the charity to climb for the first time at the gym.

To teach the kids how to find the holds, we built the equivalent of an analogue watch on the wall and taught them the instructions that their caller (the person telling them where to go from the ground) would tell them. According to the International Federation of Sport Climbing (2023), the caller can tell the climber in which direction the next hold is by using the reference of the numbers as in an analog watch or instructions such as left/right and up/down. They can also tell them how far it is (using A-B-C to indicate how far the climber would have to reach) and which type of hold they're reaching to (jug, crimp, slopper, under, etc.). For instance, a guide might tell a climber with a visual impairment that the next hold is a crimp (type of hold), at two o clock (direction), B (distance).



The representation of an analog watch to teach the children how to find the next hold

A child with blindness learning find holds while climbing

Then, to show the climbing routes to the children, we replicated a project designed by Mathew Shifrin, a climber with blindness who used Lego bricks to recreate the routes at a climbing gym as an inclusive strategy so people with blindness could feel them and memorise them before they climbed (CBS, 2020). Using Lego bricks, we recreated some of the routes at the climbing gym so the children could feel them and have an idea of the movements before they started climbing.

Example of a climbing route replicated with Legos

When they started climbing, some of the children experienced fear because they got disoriented with hight. Additionally, it became hard to listen to the instructions as they got higher. Coincidentally, the children's climbing team of the gym was training at the same time of the event, and they volunteered to help the children from the centre manage this fear. Children from the climbing team climbed alongside the children with visual impairments to guide them in finding the next holds. Listening to the voices closer to them also helped the children maintain a sense of orientation. After the initial fear, they started enjoying the activity and wanted to continue climbing different routes.

In addition to the positive effect that the children from the climbing team had in the experience of children with visual impairments trying climbing for the first time, this event also served to create awareness in the children from the climbing team, who, after the event, reflected with their coach about inclusion in climbing settings.

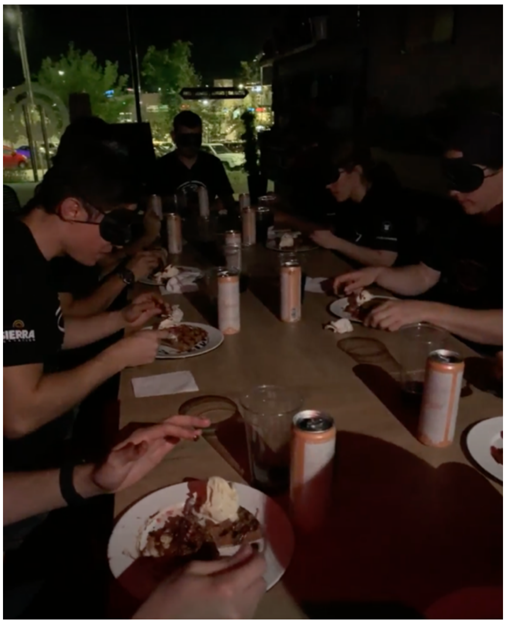
Two children from the climbing team guiding a child with blindness

After climbing, the children, their families and the staff that participated in the event sat in a circle and reflected on the experience. Most of the children enjoyed climbing and they didn't want to leave. Their families reflected that they thought their child was not going to be able to climb but were pleased they tried the activity. This event challenged their perspective of what their child could or couldn't do because of their visual impairment and contributed for them to be open to trying new activities to explore if their child liked them instead of assuming they wouldn't be able to do them. As mentioned in section 3.2.1, family is the first society from which the child will learn the first rules and associations. Therefore, working with families to challenge the current perception of blindness becomes crucial. Transforming their discourse to positive associations that can be transmitted to the child as a possibility of doing thigs differently *with* blindness instead of the absolutism of not being able to do anything *because* of blindness becomes a determining factor in the way that child will perceive and confront the social challenges that will later be presented in their life.

Participants of the event

After this event, we wanted to continue creating awareness in the climbing community. For this purpose, we brought Jesse Dufton, a professional paraclimber with sight loss from England. We had two main events called “Climbing through my eyes”, in which we invited the community to listen to Jesse’s experience with sight loss, learn how to become a caller (to guide a climber with a visual impairment) and try climbing blindfolded or with different glasses we designed that simulated visual impairments. At the end of the events, we had a dinner in the dark, in which participants we also blindfolded. During this moment, we reflected together on their experience at the event.

Participants trying climbing blindfolded



Participants having dinner blindfolded

At the end of the first event, one of the participants mentioned that he had realised he could employ people with blindness in his company. This was very significant as it meant his change in perspective that was elicited from his experience at this event could be a source of employment for people with visual impairments.

Additionally, one of the participants of the second event had retinitis pigmentosa. He’s gradually losing his sight at the age of 52 and mentioned feeling hopeless and depressed. He had never climbed before, but he heard about a “blind person climbing” and decided to go to the event and try. His wife accompanied him, she learned how to guide him to climb, and they climbed together. After the event, he mentioned he had found a new activity that he could do even when he loses his sight completely, which gave him hope.

Those moments were very meaningful to me. Through these events, we were not only making climbing an inclusive sport for people with visual impairments and changing the perception of the climbing community, but we were also able to start challenging the social perspective towards people with visual impairments, promoting job opportunities for them.

Initially, Jesse also wanted to take the children from the rehabilitation centre that had participated in the previous event to climb outdoors.

In his own experience, progressively losing his sight as a child since the age of two, his father always supported him in finding new ways to continue doing the activities he wanted to do. This support led Jesse to find new ways to continue climbing and become part of the UK para-climbing team. Jesse also continued his studies and acquired a PhD in environmental sustainability. He currently works on developing projects to protect the mountains he loves. Using his experience, he wanted to introduce the children with visual impairments that he knew had enjoyed climbing at the gym to climbing in the mountain, letting them know that it is possible to perform that activity (and many others) even when they could not see. He also wanted to share his experience with families so they could support their children from a different perspective.

We talked to the climbing gym, who were happy to lend their equipment and staff to take the children to the mountain. We then talked with the rehabilitation centre, describing in detail the itinerary and safety procedures and introducing Jesse to the council. The centre decided not to support the activity because they believed it was too dangerous for the children. This is an accurate example of the social barriers people with visual impairments face in Mexico related to the perception (or rather misperception) of blindness and the association of people with blindness being incapable.

Although some infrastructural changes are still needed to make the climbing gym fully accessible (i.e. adding a ramp or elevator so people in a wheelchair or limited mobility can access the second and third floor), they are now ready to welcome people with disabilities to the climbing area. As Qasim et al. (2014) mentioned, trying a new skill and belonging to a community can positively impact self-esteem and thus improve general well-being. Additionally, facing difficulties in climbing and overcoming them can be helpful when facing real-life obstacles.

Nonetheless, although people with disabilities are welcomed at the climbing gym, another difficulty is that most of them cannot afford a day pass or a membership. As mentioned earlier, education and jobs for people with disabilities are limited in Mexico (again the visibility of the intersection between impairment and class). Another solution would be to promote a discount or seek sponsors for people interested in the sport; nonetheless, this would mean, once again, placing people with disabilities as objects of charity. To break the cycle, I believe we need to change the perception towards people with disabilities from *unable* to *capable* of doing most of the same things as people without disabilities, *just differently*, if given the tools, support and opportunities to do so.

Currently, we are developing a documentary from the events of Jesse and the children from the rehabilitation centre trying climbing at the gym that aims to shed light on the social barriers towards people with blindness and visual impairments and promotes inclusive climbing in Mexico. With that documentary, we hope to continue challenging the perception towards people with visual impairments.

The path is still very long to make Mexico an inclusive society. As mentioned in section 2.4.1, society has a social unconscious maintained through cultural traditions and rules. Exclusion towards people with disabilities maintains the superior-inferior dynamic that places people with impairments as objects of charity and "able-bodies" as superior and saviours. Nonetheless, this position also has a secondary gain for people with impairments, who benefit from this dynamic by not having to find a job and sustain themselves economically. As job opportunities are not available, they cannot be blamed for not working or not wanting to work. Hence, they also willingly accept becoming objects of charity.

The following section discusses the current reaction of people with blindness to social exclusion by creating a non-registered organisation to beg on the streets, thus using the oppressive system to elicit a charitable reaction to earn an income.

5.7 The silent resistance: eliciting pity through begging as a passive fight against the oppressive system

Fanon described colonialism as an economic oppressive process covered in a racial discourse that serves as an explanation for the uneven division of resources (Fanon, 1967).

From a clinical perspective, the term *abnormality* is defined in Fanon's work through five approaches. First, from a statistical standpoint, as deviating from the norms that define normality as the conformity of behaviours of the majority of society. Second, a subjective distress for which a person would seek professional help. Third, the medical approach to disease. Fourth, the cultural approach that differentiates the expression of normal and abnormal from one culture to another. Fifth the inability to embody the expected ideal states (Bulhan, 1985).

Even though Fanon was using a racial discourse to explain the oppressive dynamic, if we think about the term *abnormality,* everything outside the *norm* of a society becomes *abnormal* and, thus, a subject of oppression.

Drawing from the above quote, *internalization* refers to "the process by which external, socio-historical reality is assimilated into internal and subjective reality" (Bulhan, 1985, p. 196). *Epidemialization,* a concept coined by Fanon, refers to the profound transformation in the acceptance of this subjective inferiority in relation to skin. However, we can draw from this concept to include not just the skin but the body.

We have established the relationship between the colonisation of Mexico from Spain with the implementation of the Charity Model of Disability and how this model has influenced the creation and maintenance of the perception towards people with disability. From an intersectional standpoint, we've also defined that people with disabilities in Mexico are located at the intersection between impairment and class. For this project, we specifically explored the perception towards people with blindness as useless and the object of pity (section 4.2.3.2). This perception is *internalised* by some people with blindness who register within the government system as disabled instead of working through a rehabilitation process.

This dynamic benefits both sighted people and people with blindness. People without an impairment (and usually from a higher class) seek to maintain this othering differentiation because it places them in a "superior" position, justifying access to better rights or higher status than other groups. On their behalf, people with impairments do not need to worry about finding a job or sustaining themselves economically because job opportunities are not provided. Hence they accept the position of being objects of charity and find ways to benefit from the system. Everyone's actions, regardless of their position within society, serve to maintain an unconscious social contract (Fromm, 1992).

The Mexican government provides people with a disability a fee of MXN 1,475 per month (Gobierno de Mexico, 2023). For reference, the minimum wage in Mexico is MXN 6,310, and the basic food basket is registered at MXN 3,232 (Gobierno de Mexico, 2022). To get this fee, a person with a disability cannot be registered in a job. Living independently with this fee is simply impossible.

After the interviewing process, when conducting the training for the staff members of the charity centre on the grieving process of sight loss (section 4.4), Rolando shed light on this matter, mentioning there are informal organisations created by people with disabilities, immigrants and people living in the street because of diverse situations through which they select a street corner to beg for money. He mentioned that the people with blindness he knows inside this organisation that *work* begging in the street earned more money than him having a formal job at the rehabilitation centre and that he had considered *working* on a street corner, but he preferred the dignity of having a formal job.

Nonetheless, Rolando had the opportunity to access a formal job because he could ensure continuing his higher education due to his superior cognitive capacities and social support. This highlights the accessibility problem mentioned earlier, as higher cognitive capacities and social support shouldn't be a prerequisite for education with or without a disability.

The development of this informal organisation can be related to the lack of educational and work inclusion that makes it hard for a person with blindness to reach a well-paid job. However, it also represents the extension of the Charity Model of Disability in Mexican society, in which people with blindness (or any disability) earn more money begging in the streets (eliciting pity) than in a formal job. The abnormal, Fanon said, is the one "who demands, who appeals, who begs" (Fanon, 1967a, p. 142). Hence, we're trapped in a situation with both ends bound. By impeding academic and work opportunities for people with disabilities, we're condemning them to accept an identity as *abnormal, outcast, and useless. Other.* In return, people with disabilities adopt this position and utilise it in their favour, eliciting pity with their impairment to earn an income higher than working at the *formal* jobs they could access, which are limited to minimum wage.

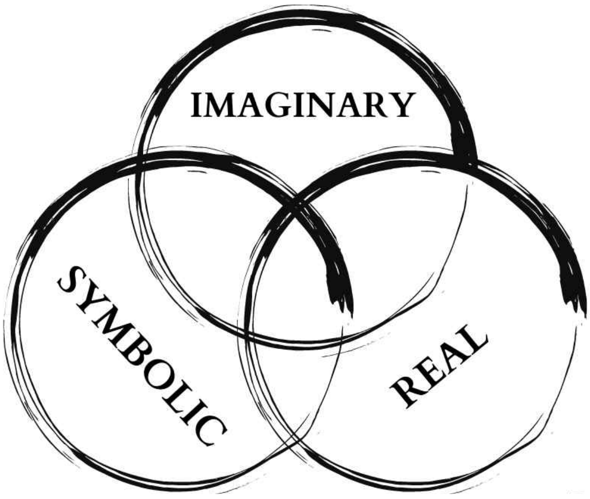
It seems like producing this informal organisation is an internalised way of coping with the social exclusion inside the oppressive power structure. It represents a passive resistance to the oppressive system that doesn't allow them to access education and a well-paid job. Inside the oppressive system, the option becomes to embody the pitiful place given by society, renouncing the possibility of higher education and (at best) earning a minimum wage through working at a factory. This alternative provides the possibility of earning the equivalent of having a well-payed job (and even more) by *using* the oppressive system to elicit pity and a charitable reaction from people.

Therefore, if *using* the system can benefit them, why would they fight the perception they're benefiting from? How do we break this pattern?

5.8 Untying the knot. The challenge of the Social Model of Disability: breaking not only the barriers, but the perception that produce and maintain the barriers

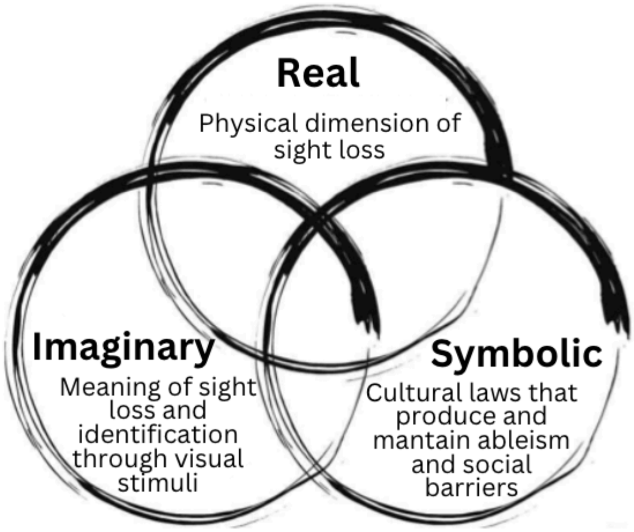
To transform the situation of oppression, it's critical to recognise the causes so that through that transformation, a new situation can emerge (Freire, 1970).

After reflecting on the elements at play regarding sight loss in a Mexican context, in this section, I theorise about how I believe these elements are intertwined and the challenges this represents. For this purpose, I use Lacan's theory of the Borromean knot. *As mentioned in section 2.3.1,* Lacan (1953) uses the Borromean knot to describe the interdependence of the three psychic dimensions: the real, the symbolic and the imaginary.



Borromean knot, by Beyond Peace (2020).

If we translate the psycho-social elements that we've reviewed through this chapter, perhaps we can think of these three psychic dimensions in the following way:



The real order can be translated to the loss of the physical possibility of seeing, the unknown and unimaginable loss of sight.

We can think of the imaginary as the meaning of sight loss, the imagination of what sight loss represents, both for people with sight loss and sighted people. Following the theory of the Mirror Stage (Lacan, 1949), for people with sight loss, this impairment represents losing the ability to find a reflection in others through visual stimuli, and thus the need to find a new way to identify themselves through others using other senses. On the other hand, sighted people, when interacting with people with blindness, are faced with the same problem. As mentioned in section 2.4.1, people with blindness cannot provide a visual gaze for sighted people to find their reflection and reconstruct their identity, as they normally do through the visual gaze of those around them. Therefore, as their need to be visually reflected is unmet, this can unconsciously provoke anxiety and anger and lead to a defensive rejecting reaction.

The symbolic order represents the set of cultural rules that structure a society to make it function. Through language, the perception of blindness has been consolidated through time as darkness and terrifying. Additionally, since the Spanish colonisation an uneven distribution of resources has favour Spanish descendants and class has defined access to medical attention, making impairments a much more predominant reality for people in the low-income classes. Therefore, society's reaction towards people with blindness has been an ableist position at the intersection of impairment and class that places sighted people as superior and portrays people with blindness as objects of pity (Goodley, 2014). The laws of the symbolic order protect the social unconscious and maintain the status quo (Fromm, 1992). This is not only pursued by sighted people but also by people with blindness. As mentioned in the previous section, some people with blindness have the secondary gain of using the system to beg in the street, eliciting pity to produce a charitable action.

In Lacan's theory, all orders have the same hierarchy, and neither is prioritised above the other. This principle applies when conceptualising sight loss within this frame: all three dimensions are crucial and coexist in an intersectional way. Every dimension is regulated by the others (Lacan, 1953).

One of the premises of the Borromean knot is that its structure is so interconnected that cutting one of the rings will liberate all three of them. This may be the case with sight loss as well. For instance, if sight loss could be prevented, as the efforts of the World Health Organization aim towards, the ring of the real order would be cut, and thus the other two orders are immediately cancelled. Another alternative would be for the meaning (imagination) of sight loss to be challenged both for people with sight loss and for sighted people (rejection) from a terrible and scary condemnation to *just* an impairment. Finally, if the symbolic structure that enables an ableist reaction towards people with blindness in society can be challenged and transformed towards an inclusive perception, the symbolic order would be cut, liberating the other two.

Through this research, we have explored both the imaginary and the symbolic realms of sight loss in Mexico. We now know that the symbolic order that facilitates an ableist society was established since the colonisation of Mexico by Spain through the adoption of the Charity Model of Disability. This model places people with blindness (and any other impairment) as inferior, useless and objects of pity, and people without disability as saviours (section 5.2).

We know that the perception of pity and uselessness has been intergenerationally transmitted through language and culture and currently excludes people with blindness from an equal position of opportunity and belonging to society by limiting their access to education and formal jobs, as well as not considering them when establishing regulation for public transportation and infrastructure and excluding them from cultural and sports events (section 5.6).

In the imaginary realm, we now understand that the exclusion of people with blindness from society has a direct impact on the adjustment process of sight loss because it represents, beyond the personal definition of this loss to each person, a symbolic death in society to which they can no longer belong. We also know that the unconscious reason for this rejection may be related to the inability of people with blindness to see sighted people. Therefore, they can’t provide them with the visual gaze they need to be recognised and reconstruct their identity constantly. By feeling unrecognised and rejected, sighted people react by excluding and resisting their own recognition of those whom they feel unrecognised by (section 5.3).

Additionally, we now understand that to maintain the status quo of this particular society, some people with blindness accept the perception of being useless and inferior. In a silent resistance, people with blindness take advantage of the charity system that oppresses and excludes them from society by accepting the secondary gain of being provided with a monthly fee by the government and by establishing a system for begging in the street, provoking pity in people without impairments and eliciting the unconscious desire of helping those in need and becoming a saviour (section 5.7).

Now, it’s time to start making efforts to untie this knot.

Echoing Crenshaw (1989), I don’t believe that a political shift to focus on the lives of the most disadvantaged and recenter the discrimination discourse at the intersection will happen tomorrow, nor is it the aim of this project. As she mentions, it is enough for now to be encouraged to look beneath the surface of the current conceptions of discrimination, at the intersection of discrimination, in the aim to develop a language to evidence this intersection with the goal to facilitate inclusion of the most marginalised groups (Crenshaw, 1989).

As mentioned in section 5.3, to create an inclusive society, the social perception towards blindness needs to be challenged and transformed from people with blindness being perceived as useless to blindness representing an impairment that doesn't have to define a person's capability or place in society.

On the other hand, challenging the social perception towards blindness also entails challenging our position (as sighted people) as "superior" and breaking the ableist and narcissistic position of "saviours", understanding the equity of every human being, regardless of their variation. It requires eliminating the "othering" position.

This “othering” could represent a defence from sighted people against the anxiety of the possibility of losing sight. Additionally, this anxiety may be unconsciously enhanced by the possibility of losing sight in a society where people with blindness don't have a place.

In Mexico, challenging the social perception towards blindness, at its intersection, also requires questioning the class structure, and urges a redistribution of resources to guarantee universal accessibility to healthcare, education, and employment opportunities.

This is the challenge of the Social Model of Disability: to change not just the barriers but the perception that produces and enhances the barriers. This entails questioning the privileged position of the able bodied, the sighted body, in its intersection (at least in Mexico) with class.

Additionally, the rejection reaction to the lack of visual cues needed for sighted people to reflect and reconstruct their identity would have to be challenged, inviting sighted people to renounce the narcissistic position of needing a visual gaze and welcome a gaze that can be delivered through other senses by people with blindness.

Perhaps if the social perception towards blindness could be challenged and transformed, the grieving process of sight loss could be different. Perhaps it could be less frightening and easier to adjust to blindness in a society where people with blindness are welcomed in the community as equals and can continue living doing the same activities they did before, just differently.

The answer, I believe, is a bet on educational inclusion to create a structural change by incorporating information about disabilities and the Social Model of Disability since elementary school to create awareness and making the necessary changes in the educational system to secure inclusion for children with disabilities in classrooms at all academic levels. This doesn’t mean that every child with an impairment would be able to attend a regular school; there are cases in which the child requires special education, i.e., severe autism. Educational inclusion doesn’t mean that every child has the same opportunities; it means that each child can access the opportunities they need to continue their education *regardless* of their impairment and not be excluded from those opportunities *because* of their impairment.

With this structural change in academic inclusion, children with or without a disability that become future leaders of companies or hold government positions will have grown with the experience that people with disabilities are not *disabled* by their impairment, thus, *hopefully*, creating a more inclusive society.

More so, this educational change demands a repositioning from the banking premise of education (in which the teacher deposits -*banks*- knowledge in their students) towards partnership between teacher and student, empowering the student to enter the dialogue and develop critical awareness towards a social situation, thus co-creating a solution. A liberation (Freire, 1970).

Nonetheless, I believe the most important lesson is not to fall into the same pattern of "saving" people with disabilities by giving them what we think they need. It is crucial in this journey to talk with people with disabilities and to ask them what they need for our community to be inclusive. Since 1900, the slogan of the Disability Rights Movement has been *nothing about us without us,* meaning no efforts should be made to *help* people with disabilities without including their voices in expressing their needs. Nonetheless, the Covid-19 pandemic’s impact on people with disabilities shed light over health and educational barriers. The Disability Rights Movement decided to change their slogan in their 2022 Global Disability Summit to *Nothing Without Us!,* meaning that the voices of people with disabilities should be considered not only in matters related to disability but in every aspect of the society they belong to.

To achieve a critical perspective, one must acknowledge one's position (Meekosha, 2010). I am a proxy that lived through a grieving process of sight loss and the exclusion challenges of Mexico with my mother, but I am not a person with a disability. Prompted by my experience and through this research, I managed to promote the creation and accessibility to emotional support in rehabilitation centres for blindness (section 5.5). I don't believe this is the answer, but I want to believe it could have helped my mother, and I believe it can be a tool that should be available to whoever wants or needs it. Additionally, this research prompted me to take action concerning the inclusion opportunities for people with blindness and visual impairments. However, I'm being careful in exploring the development of these inclusion opportunities, always including voices of people with blindness and listening to their needs, because I want to be of service, not a saviour.

The next chapter (6) presents the conclusions and reflections of this study. It aims to propose recommendations for further steps for researchers in the intersectional field of disabilities and psycho-social studies and for activists fighting for the rights of people with blindness and visual impairments, particularly in Mexico. Additionally, it suggests implications for clinical practice for counsellors working for people with sight loss.

6.- Concluding a research journey

Finalising this research represents the culmination of a journey that started 25 years ago when my mother lost her sight.

As mentioned in section 1.1, when my mother lost her sight, there weren't any rehabilitation services available, let alone emotional support. My mother lived with sight loss for nine years and never accepted blindness. She died wishing to see again. I used to think that if she would have had emotional support to elaborate on the impact of sight loss for her, our experience would have been less painful. This idea, of course, might be my wishful thinking and desire that there could have been an alternative to what we lived.

After her death, I needed to create a meaning for my experience. I set my mind to understanding the emotional impact of sight loss and finding ways to make emotional support accessible for people going through this process.

After researching the emotional impact of sight loss from a psychological perspective, this study incorporated the social dimension and aimed to explore the perception of blindness and where this perception comes from to understand the needs and obstacles to implementing emotional support for people with sight loss in the rehabilitation centres in Mexico.

As an indirect result of this research, I finally implemented emotional support for people with sight loss at the rehabilitation centres for blindness in Mexico. This section is the account of this journey.

Section 6.1 summarises the main conclusions from the data gathered through this study. Section 6.1.1 presents the reconceptualisation of sight loss from a psycho-social perspective. Section 6.1.2 presents new considerations of the impact of sight loss on identity. Section 6.1.3 presents the relevance of this research for Mexico.

Section 6.2 reflects on using the psycho-social methodology as a new dimension to explore sight loss. Section 6.2.1 reflects on the method used, the benefits and the areas of opportunity. Section 6.2.2 elaborates on the tensions between my personal experience, my profession, and my role as a researcher. Section 6.2.3 shares my reflections on the research process.

Finally, section 6.3 proposes further steps and challenges for clinicians (section 6.3.1), researchers (section 6.3.2), and activists (6.3.3) working with people with blindness and visual impairments.

6.1 From the psychological to the social. The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a summary.

As a summary, when I started researching the emotional impact of sight loss, I was solely positioned on the psychological dimension. For my bachelor's thesis, I had conducted a study that explored the factors that aided or hindered the adjustment process of sight loss. The results of the study were consistent with the literature. Factors such as optimism, determination, desire to adjust to sight loss, productivity, perseverance, independence and the presence of a support network were considered helpful in the adjustment process to sight loss. In contrast, lack of purpose, difficulty in accepting sight loss, negative self-evaluation, dependence and feelings of vulnerability were found to hinder the process (Thompson et al., 2013).

Nonetheless, there were participants who mentioned feeling depressed, scared and anxious. A participant reported consuming cocaine to avoid thinking about his sight loss. Another one mentioned having a loaded gun under his bed "for the day when he can no longer endure the pain of not being able to see" (Thompson et al., 2013, p. 80). When conducting the literature review to understand this data, we came across Thurston's research and her Five Stages of Sight Loss Model (2010) which proposes that, for a person to adjust to sight loss, they had to renounce to their identity as a sighted person and reconstruct a new identity as a person with blindness (see section 2.2 for further reference). This theory resonated with my experience with my mother, as she never renounced the possibility of seeing and, therefore, never adjusted to blindness. After we conducted this study, we recommended the centre to incorporate emotional support for people with sight loss. They replied that emotional support wasn't needed for someone to adjust to sight loss.

Although I didn't understand their adverse reaction, I thought I didn't have much information on the topic besides my personal experience and the research we had just conducted. Therefore, I decided to expand my knowledge of the emotional impact of sight loss by pursuing a Master's degree in Clinical Psychology with a Psychoanalytic Specialty. For my thesis, I conducted a theoretical research exploring Dr. Thurston's concept of sight loss as a loss of the identity as a sighted person and reconstruction of a new identity as a person with blindness from a psychodynamic perspective (Thompson, 2017). After graduating, I started working as the Coordinator of the Graduate Programmes in Clinical Psychology at my university. I went back to the centre where I had done my bachelor's thesis and offered to provide emotional support to people undergoing a rehabilitation centre without cost by master's students from the university who were training for their clinical degree. The centre's administration responded again that people with sight loss didn't need emotional support to adjust to blindness.

Having had a personal experience and after conducting an in-depth literature review and two research projects that prove the relevance of emotional support to adjust to sight loss, my next question was: Why was the centre saying emotional support isn't relevant for someone to adjust to sight loss?

I then started looking into doctoral programmes to answer this question. My initial consideration was a social degree. Nonetheless, I believe a social programme could've been reductive in focusing just the social, and I didn't want to let go of the psychological aspects. Then, I met Dr. Lita Crociani-Windland at a conference of the Association of the Psychoanalysis of Culture and Society. Through her, I learned that psycho-social studies explore not just the psychological or the social but the intersection between them (APS, 2023). This discipline was perfect for the research question I wanted to address. Therefore, I applied to the programme.

This is the first research that explores the perception of blindness using a psycho-social methodology. It follows in Thurston's footsteps, but instead of using a mixed methodology, I added a psycho-social dimension. This section summarises the main conclusions from the data gathered through this study.

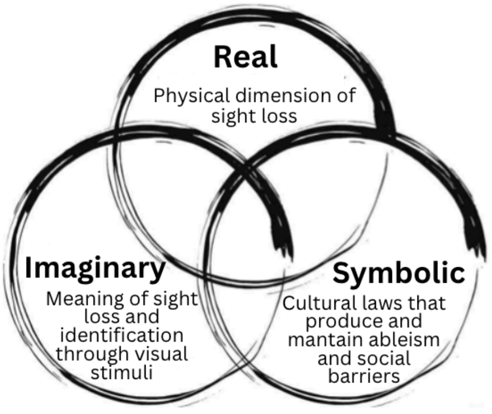
The Psycho-social discipline provided me with a platform to explore the intersection between the psychological and the social dimensions of sight loss, allowing me to reconceptualise my understanding of this process. Section 6.1.1 presents this reconceptualisation.

Dr. Thurston's Five Stages of Sight Loss model proposes that for sight loss to be accepted, the person must renounce their identity as a sighted person and reconstruct a new identity as a person with blindness. Section 6.1.2 adds to this model by presenting a reconsideration of the impact of sight loss on identity.

One of the conclusions of this research is that the social dimension plays a vital role in the adjustment process of sight loss. Although there might be shared perceptions between societies, each one has its own social unconscious that defines the perceptions, norms and laws towards people with blindness and visual impairments. This research was conducted in Mexico and shed light on the Mexican social unconscious and the dynamics at play between sighted people and people with blindness to keep the function of society by protecting that social unconscious. Section 6.1.3 summarises the Mexican social unconscious regarding people with blindness and visual impairments and the relevance of this research for my country.

6.1.1 Reconceptualizing sight loss from a psycho-social perspective

As mentioned above, this research has led me to reconceptualise sight loss by incorporating the social dimension. After conducting this study, and reconsidering sight loss as the intersection between the psychological and the social dimensions, I've come to conceptualise this process from a psycho-social perspective using Lacan's Borromean knot (1953). The Borromean knot serves as a representation of how I believe these dimensions are intertwined.



The real order can be translated to the loss of the physical possibility of seeing, the unknown and unimaginable loss of sight.

The imaginary represents the meaning of sight loss, the imagination of sight loss, both for people with sight loss and sighted people. Following the theory of the Mirror Stage (Lacan, 1949), for people with sight loss, this impairment represents losing the ability to find a reflection in others through visual stimuli, and thus the need to find a new way to identify themselves through others using other senses. On the other hand, sighted people, when interacting with people with blindness, are faced with the same problem. As mentioned in section 2.4.1, people with blindness cannot provide a visual gaze for sighted people to find their reflection, as they normally do through the visual gaze of those around them. Therefore, as their need to be visually reflected is unmet, this can unconsciously provoke anxiety and anger and lead to a defensive rejecting reaction that is manifested through exclusion and segregation.

The symbolic order represents the set of cultural rules that structure society to make it function. Through language, the perception of blindness has been consolidated through time as darkness and terrifying. Therefore, society's reaction towards people with blindness has been an ableist position that places sighted people as superior and portrays people with blindness as objects of pity (Goodley, 2014). The laws of the symbolic order protect the social unconscious and maintain the status quo (Fromm, 1992). This is not only pursued by sighted people but also by people with blindness, as both have primary and secondary gains from maintaining this status quo.

In Lacan's theory, all orders have the same hierarchy, and neither is prioritised above the other. This principle applies when conceptualising sight loss within this frame: all three dimensions are crucial and coexist in an intersectional way. Every dimension is regulated by the others (Lacan, 1953).

One of the premises of the Borromean knot is that its structure is so interconnected that cutting one of the rings will liberate all three of them. This interconnection applies to sight loss as well. For instance, if sight loss could be prevented, as the efforts of the World Health Organization aim towards (section 1.3.1), the ring of the real order would be cut, and thus the other two orders are immediately cancelled. Another alternative would be for the meaning (imagination) of sight loss to be challenged both for people with sight loss and for sighted people (rejection). Finally, if the symbolic structure that enables an ableist reaction towards people with blindness in society can be challenged and transformed towards an inclusive perception, the symbolic order would be cut, liberating the other two.

Conceptualising sight loss as the intersection between the real (the body), the imaginary (the mind), and the symbolic (the society) proposes a new way of thinking that considers the interlocking dynamic between the individual (as the meaning of sight loss is always personal) and the society (the perceptions and norms set by the social unconscious). As Lacan mentioned regarding the Borromean knot, one cannot exist without the other (Lacan, 1949). Additionally, this intersection invites to include in further studies not just the experience of people with blindness and visual impairments but also the perception of sighted people to explore the unconscious associations towards people with visual impairments and how those perceptions maintain and reinforce the status quo.

This reconceptualisation of sight loss contributes to the academic field as it proposes not just to include the individual and social dimensions but to explore the dynamic between them and the unconscious reasons that lead to creating and maintaining that dynamic. Following the psychoanalytic principle, one must recognise the unconscious forces driving our actions to be able to change them (Freud, 1914). Therefore, by researching and recognising the unconscious forces at play, the creation of inclusion strategies can be designed more specifically to target the origin of the problem.

6.1.2 Reconsidering the impact of sight loss on identity

As mentioned before, my initial perspective on the impact of sight loss on identity was based on Dr. Thurston et at. Five Stages of Sight Loss Model (2010). This model proposes that sight loss has a crucial effect on identity. For sight loss to be accepted, this model suggests, a renouncement must be made to the identity as a sighted person to reconstruct a new identity as a person with blindness. See sections 2.3.1 and 2.3.2 for further reference.

Nonetheless, Thurston's model is based on research conducted with adult population (section 2.2). The results of the present study showed that this might not be the case when sight loss occurs at a young age.

Two participants of this research lost their sight at the age of 14. One of them, Daniela, mentioned feeling enraged and sad, crying constantly and thinking that she was useless and the world was ending. She was at home for four years before her mother took her to the charity to start rehabilitation courses. On the other hand, Rolando had a different experience. He mentions feeling confused and not knowing what to do next. He felt sad for a month and a half and then decided he needed to find a way to continue his life. He mentions feeling the same way as before, he's now just "unable to see" (section 4.2.5.2).

Rolando's experience implies he doesn't feel his identity is changed in any way because of sight loss. This data adds to Dr. Thurston's research proposing that, for children and young people, sight loss might not have the same impact on identity as in adults. A possible explanation is that children's and young people's identity is still developing. Therefore, when sight loss occurs at a young age, it is incorporated as an aspect of the identity being consolidated (see section 2.3.1 for further reference on identity development) instead of having to deconstruct a more consolidated identity and construct a new definition of the self, also impacted by social constructions of what it means to be blind and the lack of inclusive provision. Although further research is needed on the topic to determine the impact of sight loss on identity in children and young people, what seem to be critical factors are positive social support and inclusion opportunities.

Here, I want to highlight the relevance of having *positive* social support, not just social support. Rolando and Daniela had social support, but it was presented in different ways. In the case of Daniela, her mother started doing everything for her, which made her feel incapable of doing anything without her mother. Additionally, she was granted her middle school degree as an act of pity from the Director. Afterwards, she was not accepted at any regular high school. On the other hand, Rolando's parents pushed him to continue studying and advocated at the school for an opportunity for him to keep going to his classes. When he finished elementary school, he got enrolled in high school, once more with his parent’s support and requesting the institution for an opportunity to prove he was able to find a way to keep up with his classmates. Afterwards, he studied a bachelor's degree in programming and is now the computers instructor at the charity (section 4.2.5.2).

Having positive social support and inclusion opportunities are factors that also play a role in the impact of sight loss on identity for adults. Positive social support is an aiding factor in the adjustment process of sight loss (Thompson et al., 2013). If the person with sight loss has a positive social network and can continue having (or can create) an independent and productive place in the society they live in, sight loss is less likely to become a defining trait in their identity. On the contrary, if the person with sight loss cannot have (or create) an independent and productive place in society, sight loss is more likely to affect identity.

Therefore, what seems to be essential when assessing the impact of sight loss on identity is to explore, additionally to the personal meaning of sight loss, the specific social unconscious associations towards blindness that define the social support and inclusion opportunities for people with blindness and visual impairments in a given society.

Nonetheless, and regardless of the efforts towards social inclusion, as Dr. Thurston's model proposes (Thurston, 2010), emotional support should be available at rehabilitation centres for whoever wants or needs it at any stage of the grieving process. This emotional support should consider the cultural aspects that may represent barriers towards adjustment, and it should be provided by trained professionals.

6.1.3 The relevance of this research for my country

As mentioned in the previous section, the social unconscious plays a significant role in the adjustment to sight loss as it will define social support and inclusion opportunities. This research shed light over the Mexican social unconscious and how it impacts the current situation for people with blindness and visual impairments, making a valuable contribution to further research and initiatives in this country.

Since the Spanish colonisation, Mexico has adopted the Christian religion in its social unconscious (section 5.2). The Christian discourse towards people with disabilities is embedded in the Charity Model of Disability. This model perceives disabilities as the rage of god or the expiation of sins. People with disabilities are perceived in this model as inferior and objects of pity (Masters, 2022).

This research showed that the main associations towards people with blindness is that they're *less fortunate or paying for their sins*. These associations lead to the belief that people with blindness and visual impairments are lesser (*poor*) beings that need help. This belief produces a *saviour mentality* embedded in charitable activities that enhance the ableist power dynamic that benefits able bodies under the discourse of *helping to earn heaven (section 4.2.3.2).*

These unconscious associations influence the current situation in Mexico regarding the prevention of visual impairments, treatment, rehabilitation, access to emotional support and inclusion opportunities (section 1.3.2).

In terms of prevention, visual health is not included in the primary health plan, making the prevention of eye conditions an inaccessible luxury for most of this country's population.

In terms of treatment, Mexico lacks resources in its public hospitals to provide attention to all people with diagnosis of eye disorders. On the other hand, treatments at a private hospital are too expensive for most people to afford, again making eye health a privilege.

Another obstacle in treatment is that ophthalmological training doesn't include the emotional impact of sight loss. As in Dr. Thurston's research in the UK (2010), in Mexico, when a person gets a diagnosis of sight loss, their emotions are not held.

Additionally, ophthalmological and rehabilitation services are not connected. Therefore, when a person receives a diagnosis of sight loss, they are not referred to rehabilitation services. Entering a rehabilitation programme depends on them previously knowing about it or someone else sharing this information with them. An example of this lack of connection is the case of Daniela, who stayed at home for four years until a taxi driver told her mother about the charity, and her mother decided to take her.

In terms of rehabilitation, Mexico doesn't have a unified guideline for rehabilitation programmes for people with blindness or severe visual impairments. This may be related to the lack of inclusion opportunities in Mexico. As there are no specific tools to learn to secure inclusion, there is no specific programme to be followed.

Regarding access to emotional support during rehabilitation, some programs mention offering this service. However, it is not specified in which way these services are provided.

Furthermore, this research evidenced that there isn't a clear pathway to access emotional support at rehabilitation centres. At the public centre, emotional support is supposed to be included in the rehabilitation plan for all people with sight loss. However, the ophthalmologist, who designs the rehabilitation plan, has lost hope in people with sight loss wanting to rehabilitate, and thus he doesn't include emotional support in their plan (section 4.2.3.4). On the other hand, at the charity, emotional support is only provided if "it's needed". Ana and Andrea, the visual rehabilitators from both centres, mentioned there isn't an explicit criterion for sending a patient to the psychology area. Sometimes, the criteria can be because they are crying in a class or they feel angry for not being able to see, which are normal emotions in a grieving process of sight loss. This evidences the lack of knowledge of the emotional impact of sight loss among the staff members (section 4.3.3). Additionally, in the charity, "negative" emotions are hidden from the benefactors in the belief that if they see them, they will withdraw their funding (section 4.2.2.1). The lack of recognition of the emotional impact of sight loss and the absence of a space to elaborate on this loss can play a significant role in the adjustment process.

Furthermore, Mexico faces another challenge regarding the provision of emotional support. As mentioned in section 2.3.2, the Mexican Psychological Society developed an ethical code for Mexican psychologists that highlights that to provide counselling or psychotherapeutic services, a psychologist must have a clinical graduate degree (Sociedad Mexicana de Psicologia, 2009). Nonetheless, although this guideline is clear, there isn't an organisation that reviews psychologists' degrees to ensure that professionals that provide counselling and/or psychotherapeutic services have the appropriate credentials. Additionally, this information is mostly unknown to people outside the psychology profession, which leads to some people seeking emotional support from untrained professionals. The public centre reflects this ignorance of the subject. The hired psychologists have a bachelor's degree, and thus they're not credentialed to treat patients (section 4.3.2). Another reason for this decision might be that hiring a psychologist with a bachelor's degree is less expensive than a master's or speciality degree. This possible reason resonates with the aim of the centre to avoid investing in what "isn't profitable" (section 4.2.2.2), and it can evidence the unconscious perception towards emotional support.

Regarding inclusion, in 2011, the General Law for the Inclusion of People with Disabilities was created in Mexico. Although this Law has clear guidelines that "guarantee" the inclusion of people with disabilities, these guidelines are not being followed.

According to the last Census, 7 million 168 thousand 178 people (5.7% of the Mexican population) have a disability. From this number, 19% do not know how to read or write (INEGI, 2021). Additionally, 80 to 90% of people with disabilities are unemployed. Of those employed, 14% are reported to be working without payment, and another 22.6% receive less than the minimum wage (UN, 2023).

Furthermore, in specific statistics regarding blindness and visual impairments, 51.7% of people with a visual condition between 6 and 29 years don't attend school, while 32.2% of the population with blindness or visual impairments cannot read or write (INEGI, 2021). Regarding working conditions, 32% of people with blindness and visual impairments older than 12 years old are economically active. Nonetheless, only 1.9% are professionals (INEGI, 2021), highlighting a clear problem in educational accessibility.

Additionally, people with visual impairments encounter several social barriers in Mexico regarding accessibility that exclude them and make it impossible to perform everyday activities in an individual, autonomous way. For example, to move from one place to another, a person with blindness would have to use public transportation. Nonetheless, there are no non-visual signals at bus stops to know which route they can wait for. Asking the people around them or the bus driver makes the person with blindness dependent on others and is almost always unsuccessful, as people with blindness are constantly ignored. These examples are another indicator of common social attitudes in Mexico.

Furthermore, the perception of inferiority and incapability is *internalised* by some people with blindness. Instead of fighting the ableist system to seek equal rights and opportunities, some people accept the position of being an object of charity and use the system to their benefit by creating an informal organisation in which they select a street corner to beg for money (section 5.7).

The development of this informal organisation can be related to the lack of educational and work inclusion that makes it hard for a person with blindness to reach a well-paid job. However, it also represents the extension of the Charity Model of Disability in Mexican society, in which people with blindness (or any disability) earn more money begging in the streets (eliciting pity) than in a formal job.

It seems like producing this informal organisation is an internalised way of coping with the social exclusion inside the oppressive power structure. It represents a passive resistance to the oppressive system that doesn't allow them to access education and a well-paid job. Inside the oppressive system, the option becomes to embody the pitiful place given by society, renouncing the possibility of higher education and (at best) earning a minimum wage through working at a factory. This alternative provides the possibility of earning the equivalent of having a well-paid job (and even more) by *using* the oppressive system to elicit pity and a charitable reaction from people.

As mentioned in section 2.4.1, the rules and norms are set in a society to protect the social unconscious and secure the function of society. Thus, the people within that society, regardless of their position, unconsciously work to maintain that social unconscious (Fromm, 1992).

By thinking about sight loss in a psycho-social way, this research sheds light over the Mexican social unconscious and how people, both sighted and with blindness and visual impairments, unconsciously maintain it.

As mentioned above, one must recognise the unconscious forces driving our actions to be able to change them (Freud, 1914). Therefore, the first impact this research brings to my country is to have a clearer idea of the unconscious perceptions that create and maintain the obstacles towards people with blindness and visual impairments and therefore be able to address them.

Additionally, as the obstacles were becoming more explicit, I couldn't just see them and not do anything about them. Prompted by my drive to change the current situation for people with sight loss in my country, this research allowed me to become an academic activist and start addressing these gaps (see section 5.5 for further reference).

6.2 Psycho-social research methodology to explore sight loss: adding a new dimension

This research is the first study that explores the perception of blindness using a psycho-social methodology. As mentioned earlier, after exploring the emotional impact of sight loss through a psychodynamic perspective (section 1.2), my interest was to explore how social perception affected the incorporation of emotional support for people with sight loss at rehabilitation centres for blindness.

This section reflects on the use of psycho-social methodology to explore the perception towards blindness. Section 6.2.1 reflects on the specific methods used for this study, their usefulness and obstacles, and recommendations of where to go next.

Section 6.2.2 reflects on the tensions between my personal experience, my profession and my role as a researcher, and how I managed those tensions through the study.

Section 6.2.3 presents my reflections on the research process as, according to psycho-social research, a researcher can never be detached from the research, and their reflections are considered valuable data.

6.2.1 The Methods

The methods I selected for this research were the Free Association Narrative Interview Method (FANI) for the staff members and the Biographical Narrative Interview Method (BNIM) for the users of the centres (section 3.3.1).

I selected the FANI method as it provided a free-associative narrative approach that allowed the participant to explore the subject at hand freely (Hollway and Jefferson, 2008). Additionally, FANI is useful for exploring identification processes, a helpful characteristic when exploring the associations that may arise when working at a rehabilitation centre for blindness when identifying themselves as a person who could become a person with sight loss.

The BNIM was selected as it is a methodology that explores lived experiences through a narrative that facilitates the expression of the inner world and the interaction with the cultural and social world (Peta, Wengraf and McKenzie, 2017). With the users, I was particularly interested in exploring not only their experience of sight loss and their perceptions towards blindness but how the culture influenced that experience and perceptions.

I believe the FANI and BNIM methods were the right place to start because they allowed me to explore the conscious and unconscious perceptions towards blindness. Most significantly, the FANI method, because of its narrative approach and the psychoanalytic principle of free association (Hollway & Jefferson, 2008), allowed me to shed light on the defences mobilised by the participants when exploring their experience working with people with blindness.

Additionally, using this methodology led me to propose a reconceptualization of sight loss as the intersection of the individual and the society, shedding light on the individual and social unconscious perceptions towards blindness and the role they play in maintaining the status quo (section 6.1.1). As mentioned earlier, this reconceptualization represents a significant contribution to the academic field as it proposes researching not just the experience of people with blindness and visual impairments but the perception of sighted people towards them and the psycho-social interaction between them. It also urges the inclusion of social components as key factors to understand the obstacles faced by people with visual impairments in a given society.

Furthermore, the psycho-social principle of reflexivity of the FANI method played a significant role both within the research and its real-life effects. The questions I asked the participants elicited reflection, making them question their associations towards sight loss and triggering unintended action, such as hiring a psychologist at the charity and asking me to train them and the staff in the emotional impact of sight loss. As mentioned in section 5.5, this reflexivity led to the incorporation of emotional support for people with sight loss at the rehabilitation centres. Even though Clarke & Hoggett (2009) define *reflexivity* as the researcher's awareness of their way of thinking and inferences, this research comes to show that is not only a characteristic experienced by the researcher but also by the participants.

As a downside, because of their interview approach, the FANI and BNIM methods aim to gather data from the verbal responses of the participants and interpersonal interaction between participants and researcher (non-verbal communication and transference- countetransference dynamics). Nonetheless, they are limited in gathering data from the systemic social dynamic within an institution or group.

As mentioned in section 3.3.1, this issue was mentioned by my examiner during the second progression exam of the PhD programme. Two obstacles disqualified ethnography as the selected methodology for this study. First, by the time I needed to conduct the interviews, the rehabilitation centres were either closed (the charity centre) or did not allow external visitors (public centre) due to the covid-19 pandemic (see chapter 3 for further reference). Hence, there was no possibility of conducting an ethnographic study. Additionally, as this is the first research conducted in this discipline that explores the perception of blindness, I felt more comfortable using a more structured way that would allow me to map where we are as a society in a more exploratory way.

Nonetheless, with this "mapping" of the available information (and now that the pandemic is over), I believe the next step is to conduct an ethnographic study.

Ethnography focuses on exploring the complex organisations of everyday life. Nonetheless, the fieldwork done via ethnography requires the researcher to bring ideas *into* the field as well as to try to get ideas *from* it. In at ethnographic study, a framework is needed beforehand to support the emerging ideas that would guide the fieldwork further (Atkinson, 2014). Therefore, I believe this research can provide an initial framework for future studies of the social associations towards blindness in Mexico.

6.2.2 My position as a researcher: the tensions between my personal experience, my profession, and my role as researcher

At my bachelor's and master's degrees, I was taught that when you conducted research, you were an outsider studying participants. Through psycho-social studies, I learned that I, as a researcher, am part of the study. My presence is already influencing the participants, as is my way of thinking and conducting the study. I also have identifiers that have meanings to the participants, and those meanings will play a role in our interaction. Researchers cannot be "neutral" and detached from their study. There is a reason we research what we research, and we're embedded in the research process. The interaction between the researcher and the research participants provides information that is as relevant as the data gathered from the interview methods.

My position through this research was unique as I was at the intersection of my personal experience as the principal caregiver to my mother with sight loss, my profession as a psychotherapist and a counsellor for people with sight loss, and my role as a researcher. Additionally, some aspects of my identity influenced my interaction with the participants. This section reviews my position as a researcher after conducting this study.

As was predictable, through some interviews, I relived my own experiences as a daughter of a mother with sight loss and . Remembering and re-living these moments elicited stronger emotional responses to interviewees' comments. When interviewing the staff members, I would feel angry and disillusioned when an ableist comment was made, such as referring to people with blindness with pity or as "incapable". On the contrary, when someone was reflective in their comments about the importance of recognising the social barriers created towards people with blindness and visual impairments, I would feel hopeful. When interviewing the users of the rehabilitation centres with the BNIM, I remembered my struggles through the medical system trying to get the resources my mother needed. I felt identified with the users. Through the interviews, I struggled to maintain a neutral position and to keep exploring their perception instead of siding with them to find answers to the problems that felt so familiar.

About the intersection between my role as a researcher and my profession as a licensed psychotherapist in Mexico and a counsellor for people with sight loss, I had the challenge of using the psychoanalytic principle of free association from the psycho-social methodology without turning the interview into a psychoanalytic session. For this purpose, I used the eliciting questions as a grounding guide for the association.

An unanticipated situation I encountered through the research was the recognising aspects of my identity that played a role throughout the research because they held a particular social meaning, either conscious or unconscious.

First, I am a woman in a patriarchal system. In agreement with the Charity Model of Disability, in which people with impairments are useless and need help, the traditional gender roles in Mexico place women as caregivers of family members when they get sick or if they have an impairment. There is a social idea that women can dedicate themselves to charity because we do not need an income, as we are economically sustained by men, our fathers or our (heterosexual) partner. This idea also endorses the charitable attitude that caring for people with disabilities should be done for free as a "good deed to earn heaven". This patriarchal dynamic was represented in the interview with Miguel, the Medical Coordinator, and Alex, the Rehabilitation Coordinator. They mentioned that "working with people with a disability takes vocation" and that "for a woman that her husband economically sustains is easy, but for a man that has to provide for a family, it's not." Throughout the research, I kept in mind this social perception and my emotional reaction towards the patriarchal system to maintain my position as a researcher to the best of my abilities, as opposed to challenging the patriarchal ideas that appeared through the interviews, particularly when interviewing male participants.

Other identifiers that played a role through the research are my skin colour (white, by Mexican standards) and my English (Thompson) and Spanish (Garcia) last names. I am aware my ascendents were on the coloniser's side. Furthermore, I studied for my Bachelor's and Master's degrees at a private university in Mexico and conducted my PhD studies at an English university. These privileges identify me as belonging to the middle to high-income class.

As mentioned in section 2.5.1, colonialism explains the uneven distribution of resources (Fanon, 1967). Through the research, I was aware of my position on the overall positive side of that uneven distribution and how that might affect my interaction with the participants.

Directors and coordinators of the rehabilitation centres also had Spanish or European last names and whiter skin than some staff members and users. My last names, skin colour and international studies facilitated access to the rehabilitation centres, presumably because I "look like them" and "talk like them". Nonetheless, I was aware of the challenge this represented for some staff members and users. Unconsciously, I might be perceived as the coloniser, bringing knowledge from overseas to help them.

After conducting this study, I have learned to reflect on my position as a researcher and the various aspects of my identity that might influence my interaction with the participants. The goal of this reflection is not to control or eliminate the influence I might have but to explore it and consider it as valuable information. I understand now that through research, one does not study the other but *something with the other.* The data and its meaning are co-constructed between the researcher and the participants. According to psycho-social studies, it is in the person's interactions with the society that the meaning lies. Accordingly, it's in the interaction of the researcher and participants, the *thirdness* (Crociani-Windland, 2018), that the meaning can emerge.

This research also led me to apply the psycho-social principle to my private practice as a psychotherapist, where I now consider the social dimension surrounding the patient with the same value as the internal, unconscious aspects of the individual. Additionally, I shifted my focus from aiming to understand the patient to the patient *and me* understanding what is happening *together*.

Reflexivity is defined as the researcher's awareness of their way of thinking and inferences (Clarke & Hoggett, 2009). This reflection represents an opportunity for the researcher to question themselves and reassess previously constructed assumptions (Crociani-Windland, 2009). With the use of reflexivity, my way of thinking has changed through this research. The following section shares my experience and learning from conducting this study.

6.2.3 Learning from experience: reflexivity through psycho-social research

After the five years through which this research took place, my way of thinking about sight loss has transformed. I started this study grounded in a psychodynamic position, thinking about sight loss as a renouncement of the identity as a sighted person and a reconstruction of a new identity as a person with blindness. I believed professional emotional support was needed for this process, and I wanted to find a way to implement this service at the rehabilitation centres for blindness that I knew were not offering it.

Reflecting at the end of this research, I understand now that this drive came from my desire to believe that if my mother could have had access to emotional support, she would have adjusted to blindness, and we wouldn't have gone through the emotional suffering sight loss entailed for both of us.

Social factors influenced the emotional impact of sight loss on my mother, such as the ambivalent support from my family (her siblings). As mentioned in section 1.1.1, they acted, consciously or unconsciously, from the perspective of the Charity Model of Disability. On the one hand, they helped us financially. On the other, they excluded us from gatherings because "we were a burden". Based on their Catholic beliefs, they prayed alongside my mother for a miracle that would give her her sight back but also justified her blindness as a purgatory on earth. Through her suffering, they said, she was saving her soul, which would go straight to heaven when she died, and she was helping other souls trapped in purgatory get to heaven. My mother accepted this perception as a meaning for her suffering.

Although she didn't have any condition that limited her mobility, she didn't try to find resources that could help her continue living independently. She never learned to use a cane or developed tools to be self-sufficient in her everyday life. She didn't try to find a job. She adopted a position of incapability and became dependent on everyone around her, especially me, as her primary carer.

I used to believe that if my mother had a space to work through what sight loss meant for her, perhaps her emotional experience wouldn't have been so painful. Maybe she could have coped with sight loss and explored ways to remain independent. I want to believe it would've also helped challenge the social associations projected onto her. However, I understand now that challenging the social perception and changing the social unconscious to provide positive support and inclusion opportunities is as crucial as providing access to emotional support.

Throughout my professional career, I've known a fair amount of people with sight loss that are independent, have a job, travel the world, etc. They recognise the social barriers but don't let them stop them from doing what they want. One of those examples is Rolando, who was able to continue studying, got a professional degree and has a stable job as the computer instructor at the charity. Another example is Jesse Dufton, the professional paraclimber with sight loss we brought to Mexico to create awareness in the climbing community (see section 5.8). What both of them had in common, which my mother lacked, was their family's support in pushing them to find ways to continue their education and activities. Therefore, one of the most crucial things I have understood through this research is that social context at different levels greatly influences the adjustment process of sight loss.

Through this research, I noticed that the rehabilitation centres represented the same situation I lived with my mother. Carlos, the council member of the charity, perceived people with blindness with pity. He thinks of them as "less fortunate" and believes he was "earning heaving by helping them" (section 4.2.3.2). At his interview, I felt enraged by his perception because it represented the same position my family placed my mother and me in. With the use of reflexivity, I was aware of that anger and prevented it from being enacted in the interviews. Nonetheless, without being conscious of it, I did influence those interviews. In the next council meeting, Carlos mentioned the relevance of hiring a psychologist instead of having a volunteer (section 4.4). Asking the questions in a non-confrontal way seemed to trigger useful reflections that were then translated into action (section 6.2.1).

After the gap in implementing emotional support for people with sight loss at the rehabilitation centres for blindness was addressed (section 4.4), I started wondering about inclusion. Therefore, I took a step further in the research and explored the inclusion services within the centres (section 4.5) to have a broader picture of the social obstacles faced by people with blindness and visual impairments in Mexico, realising that just as my family system was a representation of how the charity operates the charity is a representation of Mexican society.

The realisation of the extension of the charitable dynamic was enraging for me because it made me relive my experience with my mother within my family, for instance, when they excluded us from family gatherings, or in society in general, such as people ignoring her because she couldn't see.

Nonetheless, my perception changed after I learned that as a defence reaction towards a system that excludes them, people with blindness and visual impairments, instead of fighting the system, accept this inferior position and use the system for their benefit by creating a non-registered organisation to beg in the street, eliciting pity to earn money.

Learning about this organisation made me feel despair as I realised I was fighting to change a reality that the people oppressed by it may not want to change. Of course, not everyone is in that position, Rolando being the primary example. Nonetheless, it represents an internalised level of resignation about the possibility of change and a strategy in which rather than fighting for liberation, the power of the powerless becomes using the victim position against their oppressors. Realising this, I found the limit of my fight. I can help in the fight for liberation alongside whoever wants to fight, but I cannot fight for them.

Understanding this dynamic was personally challenging because it made me realise that is what my mother did. She accepted a place of uselessness and lived out of pity and charity from her siblings and friends. I was aware of my mother's emotional distress and my aunt's and uncle's exclusion, which enraged me and prompted me to fight it in any way I could. For instance, at a Christmas party, my aunts sat my mother in a faraway corner so she "would not disturb anyone". I told them she was not a dog and that she was going to sit with everyone else. Additionally, on occasions when she found out she got excluded from family gatherings, I would take her to the park or the mall to let her know she could go out without her siblings. I now understand I was trying to fight *for* her, believing it was my place to defend her, to save her, and failing to realise how my mother accepted and benefited from that exclusion, and that it was not my place to save her.

Prompted by my personal experience with my mother and my limited understanding of the situation, I wanted to find a way to implement emotional support for people with sight loss at the rehabilitation centres for blindness so people with sight loss can have a space to work through the emotional impact of sight loss if they wish to do so. As mentioned earlier, I thought emotionally working through sight loss would lead to the reconceptualization as an identity of a person with blindness and hence the possibility of finding different ways of doing the activities someone previously did.

Through this project, I managed to bridge this gap and implement this service at the rehabilitation centres. I also created an association through which we promote training for psychologists working with people with sight loss and inclusion projects for people with blindness and visual impairments (see section 5.5 for further information).

Nonetheless, I now understand that not everyone would choose these alternatives. Some people may decide to continue living out of charity, and some might decide to continue giving charity, rather than work towards better social inclusion. As Fromm (1992) mentions, the traditions and norms within a society serve to maintain the social unconscious. In Mexico, this social unconscious towards people with disabilities is embedded in the charity model of disability and a superior-inferior dynamic. As mentioned in the representation of the Borromean knot (section 6.1.1) for a structural change to happen (in the symbolic order), it is the social unconscious that has to be transformed. Perhaps, by changing the laws and policies, the new Human Rights Model can plant a seed that will eventually change the social unconscious over time via the transmission of new norms. Nonetheless, I understand this will not happen in my lifetime.

Through this research, I understood that even when I have an experience as a proxy, I am a sighted person, and this is not my fight. Still, I want to use my voice to create awareness and provide alternatives for people with blindness and visual impairments to be able to choose, as sighted people do, if they want emotional support when they're going through something, if they want to continue studying, if they want to work or if they want to take part in any sport and social activities. As a professional and an advocate, I believe my job is to help them, working with them, but not to save them. As this research shows, this is a dangerous position that enhances the superior-inferior dynamic in which someone is the saviour, and someone needs saving.

I am not saving anyone, nor am I superior to anyone. Through my work, I research to try to understand the psycho-social dynamic at play when it comes to people with blindness and visual impairments, I listen to what they need and work beside them as a proxy and an ally to promote awareness and inclusion.

6.3 Further steps and challenges

Through this section, I share what I see as further steps and challenges for researchers, psychologists and activists working with people with sight loss, blindness and visual impairments.

6.3.1 Psycho-social researchers: become academic activists

From this study, two main psycho-social research lines can be pursued.

One of the conclusions of this study is that further research is needed to explore the impact of sight loss on the identity of children and young people to design a specific treatment protocol for this population (section 6.1.2). Hence, the first research line entails designing and applying research protocols to explore the impact of sight loss on the identity of children and young people.

Additionally, this research was conducted using the FANI and BNIM methods as the first approach to explore the perception of blindness (section 6.2.1). These methods provided a structured framework that sets the platform for an ethnographic study, which I believe is the next step in exploring the social perception towards blindness from the inside of rehabilitation centres, institutions and social groups.

Nonetheless, although further research is essential, I want to invite researchers to become academic activists. To go beyond the high-impact publications to the real-people impact by bridging the gap between the research being conducted and published and the institutions that create regulations that impact people with sight loss, blindness and social impairments (Gardner, Thierry, Rowlandson & Steinberg, 2021).

6.3.2 Clinical implications for psychologists working with people with sight loss

As psychologists, the current challenge we face regarding working with people with sight loss is to continue disseminating training for psychologists to create a broader network of trained professionals to work with people with sight loss.

As mentioned above, upon developing further research, we also have the immediate challenge of creating a treatment protocol and training for psychologists working with children and young people with sight loss.

A further step for our profession is to create a network with the medical system so that a person diagnosed with sight loss gets referred to rehabilitation services and/or a credentialed psychologist that can provide emotional support. A system that can serve as a role model for this purpose is the Eye Care Liaison Officers (ECLOs) from the RNIB, who provide emotional support for people diagnosed with sight loss at the hospital or clinic. Then, they refer the patients to rehabilitation services within their community.

A challenge to creating this network in Mexico is that the medical profession does not value emotional support. Hence, another challenge is to create awareness of the emotional impact of sight loss within the medical community.

As a clinical recommendation, when working with a person with sight loss, it's essential to consider this loss as the intersection of the psychological and social dimensions and explore the personal meaning that sight loss represents, as well as the social structure and how it may be affecting the adjustment process of sight loss.

Additionally, it's important to remember that the objective of working with people with sight loss is to provide emotional support through the adjustment process. This emotional support should follow the premise of person-centred care, which means exploring the specific needs and challenges the person has to address to adjust to sight loss. There is not a specific psychotherapeutic approach to provide this emotional support, but rather it is recommended to use a pluralistic approach based on the patient's needs (Thurston, 2010).

Furthermore, in most cases, sight loss also affects the family or carers. Therefore, emotional support should also include working with the family either at a personal or family setting and creating support groups and networks for them to share their experiences and support each other. Beyond providing social support, group settings are particularly helpful to listen to other experiences and question self-perceptions through the guide of a trained therapist. Implementing this form of emotional support is benefitial in any case, but particularly relevant when working with children because, as we've reviewed, social support is a key component of the adjustment process and leading the child to construct an identity in which they're not disabled but rather they are working in finding new ways of doing what they would like to accomplish.

Finally, be reflective. When working with people with sight loss, be aware of your own associations, feelings and projections and how they influence the transference and countertransference.

6.3.3 Activists: Nothing without us!

Through this journey, I've learned that, although I have a personal experience as the daughter of a mother with sight loss, I am not a person with sight loss. Hence, even if I have an approximation of the experience, I cannot pretend I understand this process beyond the theory.

Therefore, my recommendation to activists and professionals working with people with blindness and visual impairments is to always listen to the people having the experience and include them in every initiative—nothing without them.

If you're a person with blindness or visual impairments, listen to other experiences to ensure the initiative is inclusive of everyone's experience. If you're a supporter, stand back and adopt a position of service, of helping a fight that isn't yours, ours, but that we can support in the way we're needed, and maybe not in the way we want to. Above everything, it is crucial to avoid adopting a saviour position so we can break the ableist superior-inferior dynamic that privileges able bodies.

Additionally, to my fellow Mexican activists and professionals who share the goal of changing the situation for people with sight loss in Mexico, I advise you to create a network. In our country, we have the challenge of questioning the predominant perception towards people with blindness and visual impairments embedded in the Charity Model of Disability. As an activist myself, one of the biggest obstacles I've encountered is that some people see my attempts to change the perception towards people with blindness from a charity perspective. For instance, when we took the children from the charity to climb for the first time (see section 5.6 for further reference), some people told me I was doing "such a great labour helping the poor kids". Through the process, I've found support through the local and international networks I've had the privilege to belong to, such as Maccia and the Sight Loss Research Network in Scottland. Therefore, my advice is for you to raise your voice and find or create a local, national or international network that shares your views and drive. You are not alone.

7.- Final Reflections

This research is the culmination of my 25-year journey to implement emotional support for people with sight loss in Mexico.

After my experience as the principal carer of my mother, I dedicated my life to understanding the grieving process of sight loss and finding a way to implement emotional support for people with sight loss at rehabilitation centres in Mexico. I understand now that the drive that pulled me so strongly came from my need to transform the painful experience that I lived with my mother into something useful.
I don't know if professional emotional support could've helped my mother; I only know that it wasn't an option for us.

Through this research, I finally got to implement emotional support for people with sight loss at the rehabilitation centre that couldn't provide it for my mother and me. Now, people with sight loss and their families can access this service and have a space to elaborate on this loss and the personal meaning it has for them.

Through this research, I was finally able to transform my experience from a painful memory into something useful, meaningful and positive. Through this research, I achieved my life's purpose.

When I finished offering the first course to train the psychologist working at the rehabilitation centre, I felt bittersweet. I wanted to celebrate with my mother, to tell her that people with sight loss and their families now have an alternative to not go through what we did. But I also felt sad because it was too late for her. I was too late.

I visited her grave with the newspaper note that said emotional support was now provided for people with sight loss in the city, and I told her we finally did it. I celebrated with her, grieved that I couldn't help her, and let her go.

"My mother can rest in peace now, and I can rest, accepting I couldn't help her, but through my experience with her, I got to offer the help I couldn't give her to others in her situation who might find it useful" (Thompson, 2022, p. 105).

8.- References

1 Genesis 1:5, Catholic Edition, Anglicized Text of The Holy Bible.

Abel, K. (1882) *Linguistics essays.* New York: The Riverside Press, Cambridge.

Alcoholics Anonymous (1981) *Twelve steps and twelve traditions.* New York: Alcoholics Anonymous World Service, Inc.

Alcoholics Anonymous (2001) *Alcoholics Anonymous- The story of how many thousands of men and women have recovered from alcoholism. 4th edition.* New York: Alcoholics Anonymous World Service, Inc.

Alcoholics Anonymous (2017) *Questions & answers on sponsorships* [online]. New York: Alcoholics Anonymous World Service, Inc. [Accessed 21 July 2020].

Allen, M. (1989) The meaning of visual impairment to visually impaired adults. *Journal of advanced nursing* [online]. 14(8), pp. 640-646 [Accessed 6 October 2019].

Anastasiou, D. & Kauffman, J. (2013) The Social Model of Disability: Dichotomy between Impairment and Disability, *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* [online]. 38 (4), pp.441–459. [Accessed 1 May 2019].

American Psychological Association (2023) Counseling. In *APA Dictionary of Psychology* [online]. [Accessed 15 March 2023].

American Psychological Association (2017) What is Psychotherapy? Available from: https://www.apa.org/ptsd-guideline/patients-and-families/psychotherapy [Accessed 15 March 2023].

Aranda, A., Viesca, C., Sánchez, G., et. al. (2003) La materia médica en el Libellus de Medicinalibus Indorum Herbis. *Revista de la Facultad de Medicina, Universidad Nacional Autónoma de México* [online]. 46(1) pp 12-17 [Accessed 6 April 2023]

Asociación Mexicana para la Atención de Personas con Discapacidad Visual (2023). *¿Quiénes somos?* Available from: http://www.amadivi.com.mx/quienes_somos.php [Accessed 23 Marzo 2023].

Association for Psychosocial Studies (2023$_a$). *About us*. Available from: www.psychosocial-studies-association.org/about/ [Accessed 20 March 2023].

Association for Psychosocial Studies (2023$_b$). Möbius band [drawing] *Logo*

Atkinson, P. (2021) *For Ethnography*. SAGE Publishing.

Barnes, C. & Mercer, G. (2010) *Exploring Disability: A Sociological Introduction* [online] *2nd Edition*. Polity Press: Cambrigde. [Accessed 20 June 2020].

Benjamin, J. (2004) Beyond Doer and Done To: an Intersubjective View of Thirdness. *The Psychoanalytic Quarterly* [online]. 73(1), pp. 5-46 [Accessed 10 February 2023].

Bergeret, J. (1983) Le toxicomania et sa psychothérapie. *Cahiers Critiques de Thérapie Familiale et de Practique des Réseaux* [online]. n. 6, p. 15-22. [Accessed 23 July 2020].

Beyond Peace (2020). *Lacanian Psychoanalysis*. Available from: https://beyond-peace.com/lacanian-psychoanalysis/ [Accessed 8 April 2023].

Bogart, K. & Dunn, D. (2019). Ableism Special Issue Introduction. *Journal of social issues.* [online]. 75(3), pp 650-664 [Accessed 21 March 2023].

Bolt, D. (2005) From blindness to visual impairment: terminological typology and the social model of disability. *Disability and Society* [online]. 20(5), pp 539-552 [Accessed 23 June 2020].

Bonsaksen, T., Brunes, A. & Heir, T. (2022) Post-Traumatic Stress Disorder in People with Visual Impairment Compared with the General Population. *International Journal of Environmental Research and Public Health* [online]. *19*(2) pp 619 [Accessed 10 March 2023].

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* [online]. 3(2). Pp. 22-101 [Accessed 15 March 2021].

Braun, V. & Clarke, V. (2022) Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a *knowing* researcher. *International Journal of Transgender Health* [online]. 4(1). Pp. 1-6 [Accessed 15 March 2023].

Bulhan, H.A. (1985) *Frantz Fanon and the psychology of oppression.* New York: Plenum Press.

Caldevilla, D. (2013) *La Comunicación a través de la Historia.* Madrid: Visión Libros.

Camara de Diputados LXIV Legislatura, Gobierno de Mexico (2020) Declaran el 15 de octubre Día Nacional de las Personas Ciegas y con otras Discapacidades Visuales [online] 15 October. Available from: https://comunicacionnoticias.diputados.gob.mx/comunicacion/index.php/mesa/declaran-el-15-de-octubre-dia-nacional-de-las-personas-ciegas-y-con-otras-discapacidades-visuales#gsc.tab=0 [Accessed 30 de June 2022].

CBS Mornings (2020). A new system could help blind people learn to rock climb. *CBS Mornings* [online]. Available from: https://www.youtube.com/watch?v=MO2zxqDuxEo [Accessed 10 April 2023].

Cipac de Aquino, M. (1523-1556) *Virgen de Guadalupe* [painting]. At: Mexico City: Basilica de Nuestra Señora de Guadalupe [online]. Available from: https://virgendeguadalupe.org.mx/en/ [Accessed 7 April 2023].

Clarke, S. and Hoggett, P (2009) *Researching Beneath the Surface: Psycho-Social Research Methods in Practice*. London: Karnac.

Collins, P.H. & Bilge, S. (2016). *Intersectionality.* Malden: Polity Press

Consejo Nacional de Evaluación de la Política de Desarrollo Social (CONEVAL) (2020) *Informes de Pobreza y Evaluación 2020* Available from: https://www.coneval.org.mx/coordinacion/entidades/Paginas/Informes_Pobreza_

Evaluacion_2020.aspx [Accessed 30 de June 2022].

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscimination Doctrine, Feminist Theory, and Antiracist Politics. *University of Chicago Legal Forum*, vol. 1989 (1), article 8.

Crociani-Windland, L. (2009) How to live and learn: learning, duration and the virtual. In: Clarke, S. and Hoggett, P., eds. (2009) *Researching Beneath the Surface: Psycho-Social Research Methods in Practice.* London: Karnac. pp. 51-78.

Crociani-Windland, L. (2018) The researcher's subjectivity as a research instrument: from intuition to surrender. In Cummins, A. and Williams, N., eds. (2018). *Further Researching Beneath the Surface: Vol. 2, Psycho-social Research Methods in Practice.* New York: Routledge. pp. 27-47.

Crudden, A., McDonnall, M. & Tatch, A. (2022) Unable to work? Characteristics of people with blindness and low vision who are out of the labor force. *Disability and Health Journal* [online]. [Accessed 9 March 2023].

Cuervo, B. (2016) La conquista y la colonización española de América. *Historia Digital.* [online]. 16(28(, pp 103-149 [Accessed 7 April 2023].

Dalal, F. (1998) *Taking the Group Seriously: Towards a Post-Foulkesian Group Analytic Theory* [online]. London: Jessica Kingsley Accessed 28 December 2022].

Datler, W., Datler, M., Hover-Reisner, N. & Trunkenpolz, K. (2014) Observation according to the Tavistock model as a research tool: remarks on methodology, education and the training of researchers. *International Journal of Infant Observation and its Applications* [online]. 17(3) p. 195-214. [Accessed 31 March 2022].

Destellos de Luz (2019) Quienes somos [online]. Available from: http://www.destellosdeluz.org/quienes-somos/ [Accessed 24 March 2023].

Diario Oficial de la Federación (2011). Ley General para la Inclusión de las Personas con Discapacidad [online]. Available from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.senado.gob.mx/comisiones/atencion_grupos/docs/LGIPD.pdf [Accessed 26 March 2023].

DIF Tabasco (2023) Centro de Atención Integral para Ciegos y Débiles Visuales. Available from:http://dif.tabasco.gob.mx/content/centro-para-ciegos-y-debiles-visuales [Accessed 21 March 2023].

Diocesis de Tepic (2014) *Simbología de la Virgen de Guadalupe. Simbiosis de las Culturas Española e India.* Available from: http://diocesisdetepic.mx/simbologia-de-la-virgen-de-guadalupe/ [Accessed 7 April 2023].

Dirth, T. & Branscombe (2017) Disability Models Affect Disability Policy Support through Awareness of Structural Discrimination. Journal of Social Issues [online]. 73(2), pp 413-442 [Accessed 20 March 2023].

Dufton, J. (2022) Interpersonal Communication, 10 November.

Dymitrow, M. (2017). Graphical representation of a Möbius strip [photograph]. In: *researchgate* [online]. Available from: https://www.researchgate.net/figure/Graphical-representation-of-a-Moebius-strip_fig1_328150097 [Accessed 8 April 2023].

Earp, B., Skorburg, J., Everett, J. & Savulescu, J. (2019) Addiction, identity, morality. *American Journal of Bioethics. Empirical Bioethics* [online]. 10:2, 136-153 [Accessed 20 July 2020].

Elliot, A. (2014). *Concepts of the self.* Cambridge: Polity Press

Ely, M., Vinz, R., Downing M., & Anzul, M. (1997) *On writing qualitative research: Living by words* [online]. London: Routledge [Accessed 23 June 2020].

European Commission (2023) *Employment, Social Affairs & Inclusion* [online]. Available from: https://ec.europa.eu/social/main.jsp?catId=1125&langId=en&intPageId=4739 [Accessed 25 March 2023].

Fanon, F. (1967). *Black skin, white masks.* New York: Grove Press.

Fanon, F. (1968). *The wretched of the earth*. New York: Grove Press.

Farris, S. (2011) The social unconscious and the collective unconscious: The Jungian perspective. In E. Hopper, & H. Weinberg, eds. (2011). *The social unconscious in persons, groups and societies* [online]. London: Routledge. [Accessed 10 April 2023].

Fight For Sight (2023) *Facts about sight.* Available from: https://www.fightforsight.org.uk/about-the-eye/facts-about-sight-loss/ [Accessed 20 March 2023].

Fimiani, R., Gazzillo, F. Dazzi, N. & Bush, M. (2022) Survivor guilt: Theoretical, empirical, and clinical features. *International Forum of Psychoanalysis* [online]. 31:3, 176-190 [Accessed 20 July 2022].

Flood, M. Martin, B. & Dreher, T. (2013) Combining academia and activism. Common obstacles and useful tools. *Australian Universities Review* [online] 55(1), pp 17-26 [Accessed 15 February 2023].

Fraiberg, S. (1977) *Insights from the blind*. United States: Queensland Braille Writing Association.

Freire, P. (1970). Pedagogy of the Oppressed. [online] New York: The Continuum International Publishing Group Inc. [Accessed 20 February 2023].

Freud, S. (1966). *Inhibition, symptom and anxiety (1926). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XX (1925-1926): An Autobiographical Study, Inhibitions, Symptoms and Anxiety, Lay Analysis and*

Other Works. Translated from German by James Strachey. London: Hogarth Press. pp. 75-176.

Freud, S. (1966). *Three essays on the theory of sexuality (1905). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. VII (1901- 1905): A Case of Hysteria, Three Essays on Sexuality and Other Works.* Translated from German by James Strachey. London: Hogarth Press. pp. 123-246.

Freud, S. (1966). *The antithetical meaning of primal words. The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XI (1910): Five Lectures on Psycho-Analysis, Leonardo da Vinci and Other Works.* Translated from German by James Strachey. London: Hogarth Press. pp. 154-161.

Freud, S. (1966). *Mourning and melancholia (1914). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XIV (1914-1916): On the History of the Psycho-Analytic Movement, Papers on Metapsychology and Other Works*. Translated from German by James Strachey. London: Hogarth Press. pp. 237-258.

Freud, S. (1966). *Remembering, repeating and working through (1914). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XII (1914-1916): The case of Shreber, Papers on Technique and Other Works*. Translated from German by James Strachey. London: Hogarth Press pp. 145-156.

Freud, S. (1966). *Wish-Fulfilment (1916). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XV (1916): Introductory Lectures on Psycho-Analysis* Translated from German by James Strachey. London: Hogarth Press pp. 213- 227.

Freud, S. (1966). *Group Psychology and the Analysis of the Ego (1921). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XVIII*

(1921): Beyond the Pleasure Principle, Group Therapy and Other Works. Translated from German by James Strachey. London: Hogarth Press. pp. 1-273.

Freud, S. (1966). *Civilisation and its discontents (1930). The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XXI (1930): The Future of an Illusion, Civilisation and Its Discontents and Other Works*. Translated from German by James Strachey. London: Hogarth Press. pp. 1-273.

Froggett, L., Manley, J. and Roy, A. (2015). The visual matrix method: Imagery and affect in a group-based research setting. *Qualitative Social Research*. [online]. 16:3. [Accessed 11 October 2019].

Fromm, E. (1992) *Obra Póstuma, 2. Lo Inconsciente Social.* [online]. Barcelona: Paidos [Accessed 10 April 2023].

Gardner, C. J., Thierry, A., Rowlandson, W., & Steinberger, J. K. (2021) From Publications to Public Actions: The Role of Universities in Facilitating Academic Advocacy and Activism in the Climate and Ecological Emergency. *Frontiers in Sustainability* [online]. 2 [Accessed 5 February 2023].

Gibbs, G. R. (2007) Thematic Coding and Categorising. In: Gibbs, G. R. ed. (2007) *Analysing Qualitative Data* [online]. London: Sage, pp. 38-55. [Accessed 15 March 2019].

Giridhar, P., Dandona, R., Prasad, M., Kovai, V. & Dandona, L. (2002). Fear of blindness and perceptions about blind people. The Andhara Pradesh eye disease study. *Indian Journal of Ophthalmology* [online]. 50(3), pp. 239-46. [Accessed 20 October 2020].

Global Disability Summit (2022) Global Disability Summit. Available from: https://www.globaldisabilitysummit.org/pages/global-disability-summit-2022-norway [Accessed 15 March 2023].

Gobierno de México (2018) Directorio de establecimientos especializados en el tratamiento de las adicciones en modalidad residencial reconocidos por la comisión nacional contra las adicciones [online] 16 August Available from: https://www.gob.mx/cms/uploads/attachment/file/377590/Directorio_actualizado_al_23_de_agosto_del_2018.pdf [Accessed 30 de June 2020].

Gobierno de Mexico (2019) Águila, nopal y serpiente, antes, durante y después de la Conquista [online]. Available from: https://www.gob.mx/semarnat/articulos/aguila-nopal-y-serpiente-antes-durante-y-despues-de-la-conquista [Accessed 7 April 2023].

Gobierno de Mexico (2019) *Día de la Bandera de México: orgullo nacional, libertad, justicia y nacionalidad* [online]. Available from: https://www.gob.mx/inafed/articulos/dia-de-la-bandera-de-mexico-orgullo-nacional-libertad-justicia-y-nacionalidad [Accessed 7 April 2023].

Gobierno de Nuevo León (2019). Centro Estatal de Rehabilitación y Educación Especial [online]. Available from: http://retys.nl.gob.mx/ubicaciones/centro-estatal-de-rehabilitacion-y-educacion-especial [Accessed 11 October 2019].

Gobierno de México (2022) Incremento a los Salarios Mínimos para 2023 [online] 1 December. Available from https://www.gob.mx/conasami/articulos/incremento-a-los-salarios-minimos-para-2023?idiom=es [Accessed 2 January 2023].

Gobierno de México (2023) Pensión para personas con discapacidad [online] 3 January. Available from: https://programasparaelbienestar.gob.mx/pension-para-personas-con-discapacidad-incrementa-a-2-mil-950-pesos-bimestrales/#:~:text=950%20pesos%20bimestrales-,Pensi%C3%B3n%20para%20Personas%20con%20Discapacidad%20incrementa%20a%202%20mil%20950,al%20periodo%20enero%2Dfebrero%202023. [Accessed 24 April 2023].

Gobierno de Puebla (2020) *8 de Octubre Día Mundial de la Vision* [online]. Available from: chrome extension://efaidnbmnnnibpcajpcglclefindmkaj/ https://ss.puebla.gob.m x/ images/areas/informate/Monitor_Vision_2020.pdf [Accessed 4 April 2023].

Goffman, E. (1963). *Stigma.* London: Penguin.

González, L. (2020) Confirman primer caso de coronavirus en NL. *El Norte* [online] 11 March. Available from: https://www.elnorte.com/aplicacioneslibre/preacceso/articulo/default.aspx?__rval=1&urlredirect=https://www.elnorte.com/confirman-primer-caso-de-coronavirus-en-nl/ar1894404?referer=--7d616165662f3a3a6262623b727a7a7279703b767a783a-- [Accessed 4 July 2020].

González, Y. (1995) El sacrificio humano entre los mexicas. *Arqueología Mexicana* [online]. 15, pp. 4-11 [Accessed 15 March 2023].

Goodley, D. (2014) *Dis/ability studies. Theorising disablism and ableism.* London: Routledge.

Government of United Kingdom (2023) *Beneficial help if you're disabled* [online]. Available from: https://www.gov.uk/financial-help-disabled [Accessed 25 March 2023].

Gross, A. (1935) The psychic effects of toxic and toxoid substances. *International Journal of Psychoanalysis* [online]. Vol. XVI, p. 425-438. [Accessed 6 July 2020].

Güemez-Sandoval, E. (2009) El papiro Ebers y la oftalmología. *Revista Mexicana de Oftalmología* [online]. 83(2), pp. 123-125 [Accessed 6 October 2019].

Harper, H. (1949) The Eye in Symbol and Symptom. *The Psychoanalytic Review* [online]. 36(1), pp. 1-21 [Accessed 6 October 2019].

Hayeems, R., Geller, G., Finkelstein, D., Faden, R. (2005) How patients experience progressive loss of visual function: A model of adjustment using qualitative methods. *British Journal of Ophthalmology* [online]. 89(5) pp. 615-620 [Accessed 6 October 2019].

Hernández, K., & Lesmes, A. (2017) La escucha activa como elemento necesario para el diálogo. *Convicciones,* [online]. 9(1), pp 83-87. [Accessed 7 March 2019].

Hernández de Tubert, R. (2021) The Mexican social unconscious—part I: The roots of a nation. *Group Analysis* [online]. [Accessed 7 March 2023].

Hidalgo y Costilla, M. (1810) *Mexican independence flag* [flag]. At: Mexico City: Museo Nacional de Historia, Castillo de Chapultepec [online]. Available from: https://mnh.inah.gob.mx/ [Accessed 7 April 2023].

Hollway, W. & Jefferson, T. (2008) The free association narrative interview method. In: Given, L. ed (2008). *The SAGE Encyclopaedia of Qualitative Research Methods*. California: Sage, pp. 296–315.

Hollway, W. & Jefferson, T. (2013) *Doing Qualitative Research Differently - A Psychosocial approach.* 2nd ed. London: Sage Publications.

Human Rights Watch (2022) *World Report 2022* [online]. Available from: https://www.hrw.org/world-report/2022 [Accessed 5 April 2023].

Hyla, A. (1943) *Divine mercy* [painting]. At: Vilnius: Sanctuary of Divine Mercy [online]. Available from: https://www.govilnius.lt/visit-vilnius/places/the-shrine-of-divine-mercy [Accessed 7 April 2023].

INEGI (2021) Estadísticas a propósito del día internacional de las personas con discapacidad (datos nacionales) [online]. Available from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.inegi.org.mx/contenidos/saladeprensa/aproposito/2021/EAP_PersDiscap21.pdf [Accessed 5 April 2023].

INEGI (2023) Encuesta Nacional de Ocupación y Empleo (ENOE), población de 15 años y más de edad [online]. Available from: https://www.inegi.org.mx/programas/enoe/15ymas/ [Accessed 6 April 2023]

Instituto Mexicano de Oftalmología (2023) *Inicio.* [online] Available from: https://imoiap.com.mx/ [Accessed 23 March 2023].

Instituto Nacional de Estadística Geográfica e Informática (2010) *Censo de Población y vivienda de México* [online] Available from: http://www.inegi.org.mx/ [Accessed 8 October 2019].

Instituto Nacional de Estadística Geográfica e Informática (2010) *Discapacidad* [online] Available from: https://www.inegi.org.mx/temas/discapacidad/ [Accessed 8 October 2019]

International Agency for the Prevention of Blindness (2020) *GBP Region Map & Estimates of Vision Loss.* Available from: https://www.iapb.org/learn/vision-atlas/magnitude-and-projections/gbd-regions/southern-latin-america/ [Accessed 21 March 2023].

International Disability Alliance (2023) *Who we are.* Available from: https://www.internationaldisabilityalliance.org/about [Accessed 9 April 2023].

International Federation of Sport Climbing (2023) *Paraclimbing resources.* Available from: https://www.ifsc-climbing.org/index.php/2-uncategorised/448-paraclimbing-resources [Accessed 15 April 2023].

Jung, C.G. (1973). The Archetypes and the Collective Unconscious (1969). *Collected Works of C.G Jung, vol. 9 (1969).* Translated from German by R.F.C. Hull. London: Routledge.

Keller, H. (1966) The story of my life. [online]. New York: Dover Publications [Accessed 5 February 2019].

Klein, M. (1975). *Envy and Gratitude (1957) The Writings of Melanie Klein, Vol. III. Envy and Gratitude and Other Works (1946-1963).* New York: The Free Press. pp. 176-235.

Kratzer, A., Luttenberg, K., Karg-Hefner, N., Weiss, M. & Dorscht, L. (2021). Bouldering psychotherapy is effective in enhancing perceived serlf-efficacy in people with depression: results from a multicenter randomized controlled trial. *BMC Psychology* [online]. 9(1) pp. 126 [Accessed 20 June 2023].

Kroger, M. (2021) *Studying Complex Interaction and Outcomes Through Qualitative Comparative Analysis: A Practical Guide to Comparative Case Studies and Etnographic Data Analysis.* London: Routledge.

Kübler-Ross, E. & Kessler, D. (2006) *Sobre el duelo y el dolor*. Barcelona: Ediciones Luciérnaga.

Lacan, J. (1953). The Symbolic, the Imaginary, and the Real. In: *Inaugural meeting of SFP.* Paris, 8 July 1953. Translated from French by Bruce Fink. Paris: École Lacanienne de Psychanalyse.

Lacan, J. (2006). The Mirror Stage as Formative of the I Function as Revealed in Psychoanallytic Experience. *In Écrits 1 (1949).* Translated from French by Bruce Fink. New York: W.W Norton & Company. pp. 75-81.

Lacan, J. (2006) *The Function and Field of Speech and Language in Psychoanalysis. In Écrits 1 (1953).* Translated from French by Bruce Fink. New York: W.W Norton & Company.

Lacan, J. (2006) Presentation on Transference. *In Écrits 1 (1960-1961).* Translated from French by Bruce Fink. New York: W.W Norton & Company.Pp. 176-188.

Lacan, J. (2019). *Desire and its Interpretation. In Seminar VI (1958-1959)*. Translated from French by Bruce Fink. New York: Polity.

Lahman, M. (2017) Ethics in Social Science Research. Becoming Culturally Responsive. [online]. New York: Sage. [Accessed 21 March 2023].

Lampl, A. & Oliver, G. (1985) Vision Without Sight. *Journal of Analytic Psychology* [online]. 30(3) pp. 297-309. [Accessed 6 October 2019].

Laplanche, J. & Pontalis, J-B. (2004) *Diccionario de Psicoanálisis*. Buenos Aires: Paidós

Larrissy, E. (2007) *The Blind and Blindness in Literature of the Romantic Period.* Edinburgh: Edinburgh University Press.

Lawson, A. & Beckett, A (2021) The social and human rights models of disability: towards a complementarity thesis. *The International Journal of Human Rights* [online]. 25(2), pp 348-379 [Accessed 20 March 2023].

Le Poulichet, S. (2012) *Toxicomanías y psicoanálisis. Las narcosis del deseo.* 2nd ed. Buenos Aires: Amorrortu.

Levecq L., Safi A., Jamart J., De Potter, P., Oustabassidis E., et al. (2017) Visual Acuity, Visual Field, and Factors Influencing Automobile Driving Status in One-Thousand Subjects Aged 18 to 59 Years. International Journal of Ophthalmology and Clinical Research [online]. 4(079) [Accessed 21 March 2023].

Loja, E., Costa, M.E., Hughes, B., & Menezes, I. (2012). Disability, embodiment and ableism: stories of resistance. *Disability & Society* [online]. 28 (2), pp. 190-203 [Accessed 6 October 2019].

Lopera, G., Aguirre, A., Parada, P. & Baquet, J. (2010) *Manual técnico de servicios de rehabilitación integral para personas ciegas o con baja visión en America Latina.* Union Latinoamericana de Ciegos

Machado, A. (2003) *Caminante, son tus huellas* (1912). *In Provervios y Cantares.Campos de Castilla*[online]. Madrid: El País. [Accessed 6 March 2023].

Manley, J. (2014) Gordon Lawrence's social dreaming matrix: Background, origins, history and development. *Organizational and Social Dynamics* [online]. 14 (2): 322-341 [Accessed 6 October 2019].

Manley, J. (2018). Every human being is an artist": from social representation to creative experiences of self. In Cummins, A. and Williams, N. (2018). *Further Researching Beneath the Surface (Volume 2): Psycho-social Research Methods in Practice* [online]. New York: Routledge. pp. 97-120 [Accessed 6 October 2019].

Masters, A. (2022) Considering a case for rights and charity. *International Journal for the Study of the Christian Church* [online]. 22(1), pp 58-74 [Accessed 20 March 2023].

Mata, S. (2020) *La Noche Triste y la Purísima. El secreto de la Virgen de Guadalupe*. [online]. Madrid: Sekotia. [Accessed 7 April 2023].

Mayer- Faulkes (2014) *El fotógrafo ciego. Evgen Bavcar en México.* México: Conaculta.

Meekosha, H. (2010). Decolonising disability: thinking and acting globally. *Disability & Society* [online]. 26:6, 667-682 [Accessed 27 December 2022].

Menzies Lyth, I. (1960). Social systems as a defense against anxiety: An empirical study of the nursing service of a general hospital. In Trist, E. and Murray, H., Eds. (1990). *The Social Engagement of Social Science Vol. 1: The Socio-Psychological Perspective.* London: Free Association Books, pp. 439-462.

Monbeck, M. (1973) *The Meaning of Blindness.* Bloomington: Indiana University Press.

Moran, L. & Caetano, A. (2021). Biographical research through the looking glass of social distancing: reflections on biographical interviewing and online technologies in pandemic times. *Irish Journal of Sociology* [online]. 30:2 [Accessed 31 March 2022].

Murray, S. (2004). *Needs of grieving adventitiously visually impaired adults: From insight to ability.* PhD, University of South Africa.

National Democratic Institute (2022). *From "nothing about is without us" to "nothing without us"* [online] 28 March. Available from: https://www.ndi.org/our-stories/nothing-about-us-without-us-nothing-without-us [Accessed 2 January 2023].

Neri-Vela, R. (2016) Los conocimientos oftalmológicos en el México prehispánico. *Revista Mexicana de Oftalmología* [online] 90(1), pp. 8-10. [Accessed 20 March 2023].

Novartis (2017) Novartis global survey shows 85% fear blindness, only 33% have regular eye examination. Available from: https://www.novartis.com/ph-en/news/media-releases/novartis-global-survey-shows-85-fear-blindness-only-33-have-regular-eye-examination [Accessed 20 March 2023].

Oliver, M. (2013) The social model of disability: thirty years on. *Disability & Society* [online]. 28 (7), pp.1024-1026 [Accessed 1 May 2019].

Organisation for Economic Co-operation and Development (2019) *Education at a Glance Database.* Available from: http://stats.oecd.org. [Accessed 4 March 2022].

Organizacion Nacional d Ciegos de España (2023) *A tu lado siempre.* Available from: https://www.once.es/servicios-sociales/a-tu-lado-siempre [Accessed 6 March 2023].

Oviedo-Cáceres, M., Arias-Pineda, K., Guisasola, L., Montoya, P. & Guisasola, V. (2021) “My disability does not measure me: it is a way of living and being in the world” meanings of social inclusión from the perspective of people with visual impairment. *British Journal of Visual Impairment.* [online] 41(1) [Accessed 4 March 2023].

Oyarzabal, C. (2007). El mundo “visual del ciego”. Psicoanálisis y Discapacitados. [online]. [Accessed 6 October 2019]

Pan American Health Organization (2023) *Visual Health.* Available from: https://www.paho.org/en/topics/visual-health [Accessed 21 March 2023].

Penna, C. & Amorim, C. (2015) Reflections on the Concept of Social Unconscious. Revista Subjetividades, Fortaleza [online]. 15(1), pp 46-56 [Accessed 10 April 2023].

Penna, C. (2022) The Mexican social unconscious: ‘Confusion of tongues’ in tripartite matrices of colonized countries. Response to ‘The Mexican social unconscious—Part I: The roots of a nation’ and ‘Part II: Politics and group analysis’ by Reyna Hernández de Tubert. *Group Analysis* [online] [Accessed 8 December 2022].

Peta, C., Wengraf. and McKenzie, J. (2018) *Facilitating the voice of disabled women: the biographic narrative interpretative method (BNIM) in action. Contemporary Social Science: Journal of the Academy of Social Sciences* [online]. *14(2): 1-13. [Accessed 15 March 2019].*

Piaget, J. (1936) *Origins of intelligence in the child.* [online]. Translated from French by Kegan Paul. London: Routledge. [Accessed 20 February 2019].

Pickover, C. (2006). *The Möbius Strip: Dr. August Möbius's Marvelous Band in Mathematics, Games, Literature, Art, Technology, and Cosmology*. [online]. New York: Thunder's Mouth Press. [Accessed 23 March 2023].

Plan International (2020) Women and girls' rights 'precarious' in Middle East and North Africa. *Plan International* [online] 10 December. Available from: https://www.hrw.org/report/2022/08/08/racial-discrimination-united-states/human-rights-watch/aclu-joint-submission [Accessed 17 March 2023].

Ponder, J. (2016). Ableism and countertransference challenges in psychotherapy with blind adults. Proceedings of the the 2nd Annual Conference of the Association of Psychosocial Studies, Bristol, 30 June- 2nd July 2016.

Postmes, T. et al. (2010) *Rediscovering social identity: key readings*. [online] New York: Psychology [Accessed 10 March 2023].

Pybis, J., Thurston, M., Dennison, C. M., Broom, M., Miller, A. (2016) The nature of emotional support and counselling provision for people with sight loss in the United Kingdom. *British Journal of Visual Impairment* [online]. 34(2), pp. 169-178 [Accessed 14 February 2021].

Pyda, G., Rakhi, D., Mudigonda, P., Vilas, K. & Lalit, D. (2002) Fear of Blindness and Perceptions about Blind People. The Andhra Pradesh Eye Disease Study. *Indian Journal of Ophthalmology* [online]. 50(3) pp 239-246 [Accessed 20 March 2023].

Qasim, S., Ravenscroft, J. & Sproule, J. (2014). The effect of Karate practice on self-esteem in young adults with visual impairment: A case study. Australian Journal of Educational & Developmental Psychology. [online]. (14) 167-185. [Accessed 20 June 2023].

Ravenscroft, J., Davis, J., Bilgin, M. & Wazni, K. (2019) Factors that influence elementary school teachers' attitudes towards inclusion of visually impaired children in Turkey. *Disability & Society* [online]. 34:4, 629-656 [Accessed 4 March 2023].

Real Academia de la Historia (2023) La Malinche. Available from: https://dbe.rah.es/biografias/12987/la-malinche [Accessed 15 March 2023].

Reinhardt, J. (2001) Effects of Positive and Negative Support Received and Provided on Adaptation to Chronic Visual Impairment. *Applied Developmental Science* [online] 5(2), 76- 85. [Accessed 8 October 2019].

Reyes, C. (2016). Aplican Ley de Talión a iraní que dejó ciega a una niña de 4 años tras lanzarle cal viva. *Agencia de Noticias France-Presse* [online] 9 November. Available from: https://www.infobae.com/america/mundo/2016/11/08/iran-aplicaron-la-ley-del-talion-contra-el-agresor-de-una-nina-que-quedo-ciega/#:~:text=Est%C3%A1%20contemplada%20en%20la%20sharia%2C%20o%20ley%20isl%C3%A1mica&text=Un%20iran%C3%AD%20fue%20cegado%20este,citado%20por%20la%20agencia%20Isna. [Accessed 4 April 2019].

Rooney, K., Newton, N., Carney, F., Soukhanov, A., Wright, E., Brown, L., Ayto, J., Jackson, D., Konopka, R., Edwards, P. & Webb, W. (1999) *Encarta World English Dictionary* [online]. London: Bloomsbury [Accessed 20 July 2021].

Rösing, I. (1999) Stigma or sacredness. Notes on dealing with disability in an Andean culture. In: Holzer, B., Vreede, A. & Weigt, G., eds. (1999) *Disability in Different Cultures. Reflections on Local Concepts.* [online]. Die Deutsche Bibliothek, pp 27-43 [Accessed 15 March 2023].

Rosique, M., González, C. & Sanz, T. (2014) Acompañamiento terapéutico: práctica y clínica en un hospital psiquiátrico. *Revista de la Asociación Española de Neuropsiquiatría* [online]. 34(123), pp 583-587 [Accessed 15 March 2023].

Royal National Institute for the Blind (2022) *See the Person, not the sight loss.* Available from: https://www.rnib.org.uk/our-campaigns/see-the-person/ [Accessed 20 November 2022].

Royal National Institute for the Blind (2023) *Sight loss conselling.* Available from: https://www.rnib.org.uk/living-with-sight-loss/community-connection-and-wellbeing/sight-loss-counselling/ [Accessed 20 April 2023].

Sánchez, A., Robles, N., Fukushima, E., & Ferrer, J. (2019) Informe sobre la situación del consumo de drogas en México y su atención integral 2019. *Gobierno de México* [online]. 7 March Available from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.gob.mx/cms/uploads/attachment/file/477564/Informe_sobre_la_situacio_n_de_las_drogas_en_Me_xico_.pdf [Accessed 14 July 2020].

Sandoval, H., Pérez-Neri, I., Martínez-Flores, F., Del Valle-Cabrera, M. & Pineda, C. (2016) Disability in Mexico: a comparative analysis between descriptive models and historical periods using a timeline. *Salud Pública de Mexico* [online]. 59 (4), pp. 429-436 [Accessed 6 October 2019].

Saussure, F. (1916). *Course in general linguistics.* [online]. London: Duckworth. [Accessed 6 October 2021].

Sartre, J-P. (2003) Being and Nothingness (1943) [online]. Translated from French by Hazel Estella Barnes. London: Routledge [Accessed 6 October 2021].

Searless, H.F. (1955) The informational value of the supervisor's emotional experiences. *Psychiatry: Journal for the Study of Interpersonal Processes* [online]. 18, pp 135-146. [Accessed 15 February 2023].

Secretaría de Salud, Gobierno de Puebla (2020). Día Mundial de la Visión [online] 8 October. Available from: https://ss.puebla.gob.mx/prevencion/informate/item/1183-dia-mundial-de-la-vision#:~:text=Se%20calcula%20que%20entre%2040,degenerativa%20(5%25)%20y%20malformaciones [Accessed 30 June 2022]

Sociedad Mexicana de Psicología (2009) *Código ético del psicólogo* 4th ed. [online]. Mexico: Trillas [Accessed 16 March 2023].

Sófocles (429 b.C.) *Edipo Rey*. Reprint. Chile: Editorial Cuarto Propio, 2000.

Spitz, R. (1951) The Psychogenic Diseases in Infancy – An Attempt at their Etiological Classification. *Psychoanalytic Study of the Child* [online] 6, pp. 225-275 [Accessed 6 October 2019].

Taylor, C. (1990). *Sources of the Self* [online]. Cambridge: Harvard University Press. [Accessed 24 November 2021].

The Eye Associates (2023) *Blindness- a Major Fear.* Available from: https://www.theeyeassociates.com/blindness-a-major-fear/ [Accessed 20 March 2023].

The International Agency for the Prevention of Blindness (2023) *About Us.* Available from: https://www.iapb.org/ [Accessed 9 March 2023].

The International Agency for the Prevention of Blindness (2019) *Vision Alliance.* Available from: https://www.iapb.org/vision-alliance/ [Accessed 9 October 2019].

The International Agency for the Prevention of Blindness (223) *Latin America.* Available from: https://www.iapb.org/iapb-regions/latin-america/ [Accessed 9 March 2023].

Thomas, D. (1951). Do not go gentle into that good night [online]. Botteghe Oscure. [Accessed 9 January 2019].

Thompson, L. M., Salinas, M, Herrera, H, González, S, & Contreras, D, (2013) *Proceso de adaptación en personas invidentes a causa de un accidente o enfermedad*. Bachelors, Universidad de Monterrey.

Thompson, L. M. (2017) *La muerte en vida: algunas reflexiones sobre el duelo en la invidencia adquirida.* Masters, Universidad de Monterrey.

Thompson, L. M. (2022) Becoming my mother's eyes. *Journal of Psychosocial Studies* [online]. 15(2): 98-106. [Accessed 9 April 2023].

Thurston, M. (2010) An inquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted people. *Counselling and Psychotherapy research* [online]. 10(1), pp. 3-12 [Accessed 6 October 2019].

Thurston, M., Thurston, A., & Mcleod, J. (2010) Socio-emotional effects of the transition from sight to blindness. *The British Journal of Visual Impairment* [online]. 28(2), pp. 90-112 [Accessed 14 February 2021].

Thurston, M., Mcleod, J., & Thurston, A. (2013) Counselling for sight loss: using systematic case study research to build a client informed practice model. *The British Journal of Visual Impairment* [online]. 31(2), pp. 102-122 [Accessed 14 February 2021].

Tuttle, D., & Tuttle, N. (1996). *Self-esteem and adjusting with blindness.* 2nd ed. [online]. Springfield: Charles C. Thomas Publisher [Accessed 6 October 2019].

UK Vision Strategy. (2011) *Seeing it my way.* Available from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.choiceforum.org/docs/simw.pdf [Accessed 9 October 2019].

UNESCO (2020) *UNESCO report on inclusion in education shows 40% of poorest countires did not provide specific support to disadvantaged learners during COVID-19 crisis* [online]. Available from: https://www.unesco.org/en/articles/unesco-report-inclusion-education-shows-40-poorest-countries-did-not-provide-specific-support [Accessed 25 March 2023].

UNICEF (2019) *Situational Analysis of Women and Girls in the Middle East and North Africa. A decade review 2010- 2020* [online]. Available from:

https://www.unicef.org/mena/reports/situational-analysis-women-and-girls-middle-east-and-north-africa [Accessed 17 March 2023].

UNICEF (2021) *The World's nearly 240 million children living with disabilities are being denied basic rights.* [online] Available from: https://www.unicef.org/kosovoprogramme/press-releases/worlds-nearly-240-million-children-living-disabilities-are-being-denied-basic-rights [Accessed 23 March 2023].

Union Latinoamericana de Ciegos (2023) *Quienes somos.* Available from: http://www.ulacdigital.org/quienes-somos/ [Accessed 23 March 2023].

United Nations (2006) *Convention on the Rights of Persons with Disabilities and Optional Protocol* [online]. Available from: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf [Accessed 25 March 2023].

United Nations (2023) *Disability and Employment. Fact Sheet 1.* [online]. Available from: https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities/disability-and-employment.html#:~:text=Global,between%2050%25%20and%2070%25. [Accessed 23 March 2023].

United States Government (2023) *SSDI and SSI benefits for people with disabilities* [online]. Available from: https://www.usa.gov/social-security-disability [Accessed 25 March 2023].

Valente, C. (2019) What makes an activist scholar?: Reflexivity and the internal conversation of academic activists. *Social Alternatives* [online]. 38(3), pp. 7-13 [Accessed 4 December 2022].

Von Klein, CH. (1905). *The medical features of the papyrus Ebers*. [online]. Chicago: Chicago Press [Accessed 6 October 2019].

Walsh, G.M (2020). Challenging the hero narrative: Moving towards reparational citizenship education. *Societies* [online]. 10 (2), p. 34. [Accessed 6 October 2022].

Wengraf, T. (2001). *Qualitative research interviewing: biographic narrative and semi-structured method* [online]. London: Sage Publications [Accessed 6 October 2019].

Wengraf, T. (2018). BNIM short guide bound with the BNIM detailed manual. Interviewing for life histories, lived periods and situations and on-going personal experiencing using the biographic-narrative interview method (BNIM) [online]. London: Sage Publications [Accessed 6 October 2019].

Wickström, G. & Bendix, T. (2000) The "Hawthorne effect"—what did the original Hawthorne studies actually show? *National Library of Medicine.* [online]. 26(4), pp 363-367. [Accessed 6 April 2023].

Williams, J. (2020) Back to Basics: What Do Blind People See? ACBVI Blog [blog]. 21 September. Available from: https://www.acbvi.org/blog/back-to-basics-what-do-blind-people-see [Accessed 23 March 2023].

Williams, N. (2021). *Mapping Social Memory: A Psychotherapeutic Psychosocial Approach.* Palgrave: Switzerland

Winnicott, D.W. (1971). *Playing and Reality*. London: Routledge.

Wittgenstein, L. (1961). *Tractatus Logico-Philosophicus*. [online]. London: Routledge [Accessed 6 October 2021].

Wobeser, G. (2013) Mitos y realidades sobre el origen del culto a la Virgen de Guadalupe. [online]. Universidad Auónoma de México [Accessed 26 March 2023].

World Blind Union (2021) *2022-2025 Strategic Plan- Short Form* [online]. Available from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://worldblindunion.org/wp-content/uploads/2022/08/WBU-2022-2025-Strategic-Plan.pdf [Accessed 4 April 2023].

World Blind Union (2023) *Our Work.* Available from: https://worldblindunion.org/programs/ [Accessed 4 April 2023].

World Blind Union (2023) *Who are we.* Available from: https://worldblindunion.org/about/ [Accessed 25 April 2023].

World Health Association (2023). *Blindness and vision impairments.* Available from: https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment [Accessed 4 April 2023].

World Health Association (2022). *Countries in the European Region commit to disability-inclusive health systems and societies* [online] 14 September. Available from: https://www.who.int/europe/news/item/14-09-2022-countries-in-the-european-region-commit-to-disability-inclusive-health-systems-and-societies [Accessed 4 April 2023].

World Health Association (2023). *International Classification of Diseases 11th Revision. The global standard for diagnostic health information.* Available from: https://icd.who.int/en [Accessed 4 April 2023].

World Health Organization (2020) *Substance abuse.* Available from: https://www.who.int/topics/substance_abuse/en/ [Accessed 13 July 2020].

World Health Organization (2019) *World Report on Vision.* Available from: https://www.who.int/publications/i/item/9789241516570 [Accessed 30 June 2020].

Yasmin S. (2012) An integrated low vision service: Sri Lanka. *Community eye health.* [online]. 25(77), pp 16 [Accessed 16 March 2023].

Zerubavel, N. & O'Doughterty Wright, M. (2012) The Dilemma of the Wounded Healer. *Psychotherapy* [online]. 49(4), pp 482-491 [Accessed 4 October 2022].

9.- Appendix

9.1 Seeing blindness through the visual matrix

This study was conducted as part of the "Researching Beneath the Surface" module undertaken for research credit as part of the PhD programme. This research explored the unconscious associations towards people with blindness by sighted people through the Visual Matrix Method. The study was conducted at a private university in Mexico.

Method

The Visual Matrix Method works towards understanding the unconscious images linked with affect. This method, developed from the Social Dreaming Method, leaves the emphasis on dreaming but keeps the imagery in the mind and free association (Froggett, Manley & Rosy, 2015), with the main focus on the expression of affect through shared unconscious visualisations (Manley, 2018). The meaning emerging in this interaction, at this particular moment, will not necessarily come in words, as sometimes "words are not enough" (Manley, 2018, p.97).

Because images are a crucial component in the visual matrix, this would not be an inclusive method towards a person with a visual impairment. However, this research aimed to explore the perception of blindness constructed by the sighted society, presumably made through visual stimuli. This method was mainly selected to explore the visual representation that sighted people hold towards blindness.

The First Attempt

The sample was selected by convenience, as the researcher was teaching two groups of the class "Fundaments of Clinical Psychology", a first-year course of the bachelor's in clinical psychology at a private university in Mexico. The researcher explained the study in both groups. The students of both classes (30 and 23) were invited to participate in the visual matrix. The activity was scheduled to occur outside the frame of the classes at a time, date and location set on similar conditions as one class reposition. After explaining the activity, they were asked to send a picture by email of whatever comes to mind when thinking about blindness. Two students sent a picture by email to the researcher (see Fig. 1 and 2), but no one showed up for the activity.

The Second Attempt

As a second attempt, the visual matrix was introduced to one of the groups as a pedagogical activity inside the research module of the class to present a new methodology. This particular group was selected for practical reasons, as the other group was taught in an auditorium, and the chairs could not be moved, making it impossible to create the snowflake seating arrangement.

The selected group had 23 enrolled students, all females between 18 and 22 years old, 21 of Mexican nationality and 2 Colombian students in an exchange semester. The 19 students that showed up to class that day were given a consent form, which was explained and read along with the researcher to clarify any questions that may arise. All students were given a choice to participate, and it was explained to them that if they chose not to or leave at any time during the activity, it would not affect their grades or assistance registration. The 19 students decided to participate.

Pre-matrix stimulus material

Stimuli for the visual matrix have included a slide show of images, the creation of images, a film or attending an art exhibition (Ramvi, Manley, Frogget, et al., 2019).

In this activity, a slide show of images was created by the researcher, including the two images previously sent by the students (see figures 1- 12). Before showing the images to the students, a brief relaxation technique was made to bring them to the here and now and to reflect on the images, their thoughts and feelings. This relaxation technique included closing their eyes and taking five deep breaths.

The following images were the ones used as a visual stimuli for the visual matrix:

Figure 1. Picture sent by student 1

Figure 2. Picture sent by student 2

Figure 3. Picture for visual matrix

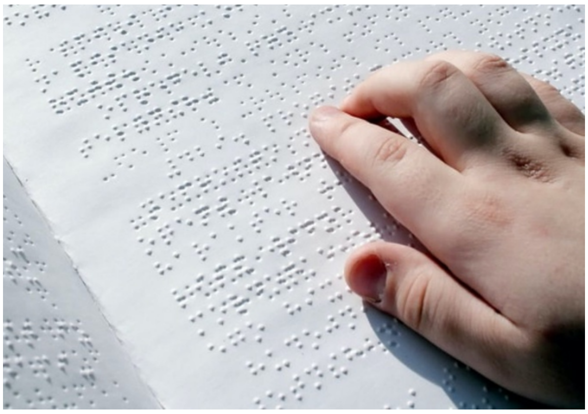


Figure 4. Picture for visual matrix

Figure 5. Picture for visual matrix

Figure 6. Picture for visual matrix

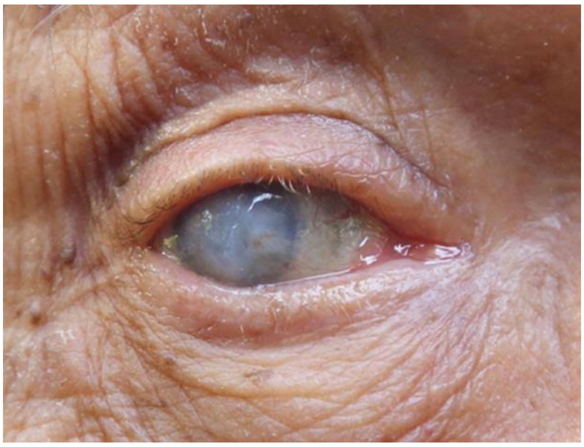


Figure 7. Picture for visual matrix

Figure 8. Picture for visual matrix

Figure 9. Picture for visual matrix

Figure 10. Picture for visual matrix

Figure 11. Picture for visual matrix

Figure 12. Picture for visual matrix

The Visual Matrix

After looking at the images, the students and the researcher participated in the visual matrix. During a visual matrix, typically lasting for an hour, participants are arranged in the snowflake-seating configuration (see Figure 13):

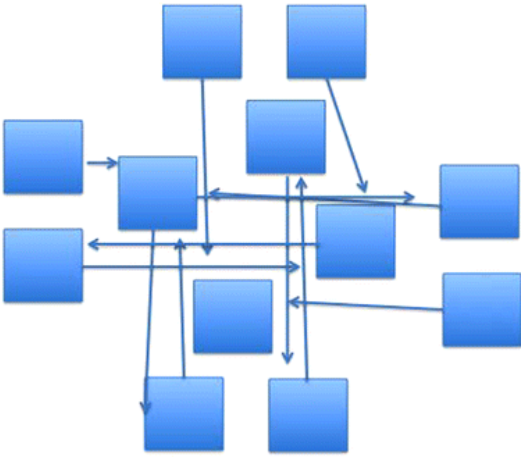


Figure 13. Snowflake- seating configuration

This configuration, taken from the social dreaming method (Manley, 2014), invites the participants to not talk to each other as in a group activity but to be part of a collective body in which images and associations are offered in a shared space. Without direct visual contact between the participants, letting go of the anguish of being seen can enhance free association. As the visual matrix session develops, memories and expressions charged with emotions are elicited in the participants and shared in a contained space that protects them from the anxiety of raw, unconscious material (Ramvi, Manley, Frogget, et al., 2019), providing a "potential space" on which to create (Winnicott, 1971).

The role of the researcher, also participating in the activity, is to a) become the facilitator to elicit images and memories; and b) be the source of containment for the unconscious material to emerge. For this to happen, the researcher has to explore their containment capacity, tolerance to frustration, and unknown unconscious reaction to the participants and the material (Ramvi, Manley, Frogget, et al., 2019).

Post-matrix discussion and analysis process

Following the visual matrix session, participants were asked to move to a circle to make a post-matrix discussion about the emerging themes. This function as the first step of the analysis, marking the frame of the themes and offering an opportunity for the participants to debrief and process the anxiety they may have felt during the matrix (Ramvi, Manley, Frogget, et al., 2019).

The Visual Matrix was done in Spanish, transcribed and translated to English to be analysed using thematic analysis. Thematic analysis (Clarke & Braun, 2016) is a method usually used in qualitative research because it provides a tool, as opposed to a confined framework, for identifying, analysing and interpreting patterns of the meaning of the material that emerges. This type of analysis locates meaning through the identified themes. The aim of this methodology is not to summarise the data but, guided by the research question, to produce a rigorous analysis of the emergent content. The themes and subthemes provide a framework for the researcher to report the analysis made of meaning and observation. Thematic analysis is a methodology that can be used to question personal and social patterns that emerge around a topic (Clarke & Braun, 2016).

In order to explore the content from both a psycho-social perspective and maintain the cultural frame, two groups of experts were created to participate in the data analysis. The first group was composed of two researchers (one English and one Italian) from the University of the West of England who are familiar with the psycho-social studies methodology. The second group was composed of two Mexican Psychoanalysts and a Spanish Neurosciences researcher that has been living in Mexico for the last five years. This group provided their expertise while being familiar with the culture in which the research took place. Both groups met once, and two thematic analyses were made, one in English and one in Spanish.

Results

After the themes and subthemes were identified by the expert panels, a thematic map was created to visually identify the relation between the emerging themes (see figure 14):

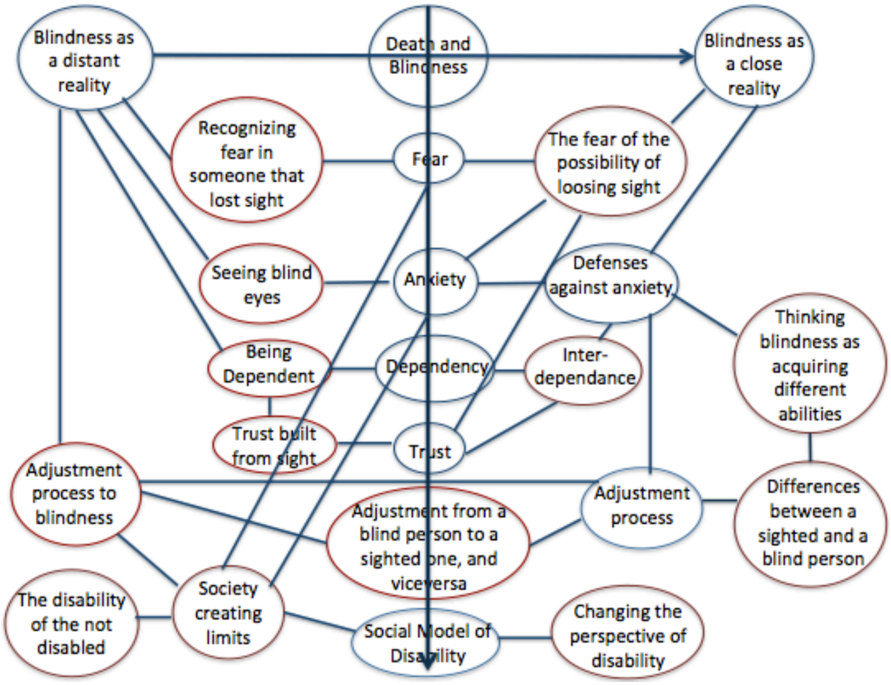


Figure 14. Thematic map

It is important to note that this study was possible at its second attempt when presented as a pedagogical activity. During the first attempt, made as an invitation to participate in a different time and place than the class, no one showed up. Although this cannot be reduced to one explanation, it might present a rejection reaction towards speaking about one's understanding of blindness.

At the beginning of the matrix, the participants started to talk about blindness from experiences they had with their grandparents or great-grandparents, referring to

blindness as a distant reality, only possible to "the other", tainted by feelings of anxiety about what it must be like" to the other" not to be able to see.
The snowflake-seating configuration does not allow direct visual contact to facilitate free association by avoiding talking directly at one another (Manley, 2014). During the activity, whenever a participant was talking, they would turn around, looking for eyes on which to reflect themselves, particularly those of the researcher. As all participants were sighted, we can refer to this phenomenon as the necessity to find oneself in the reflection of the other (Lacan, 1949).

First, participants tried to conceptualise blindness as a distant reality, associating it with old age and their experiences of their grandparents gradually losing sight. The discussion continued with the participants focusing on the gaze they saw from people with blindness in the pictures. One of the participants described them as "without expression". The eyes of these faces, the participants said, were not focusing anywhere and appeared to be without life. These comments shifted the matrix towards the resemblance between death and blindness. "It is like dead people, but alive" was one of the associations. This resemblance can be traced back to the Ancient Hebrew culture, where blindness, as an unknown condition, was a synonym for death (Güemez-Sandoval, 2009).

The possibility of death presented an unthinkable reality to the participants: If I can die, I can lose my sight. This association generated a one-minute pause, followed by the emergence of fear and anxiety. From trying to understand what someone with blindness might feel, the participants were now faced with the challenge of exploring what they would feel themselves, given the possibility of losing sight.

Defences against anxiety were activated in the group in an immediate attempt to rationalise information. First, the group tried to think and understand the differences between a sighted person and a person with congenital blindness, wondering if a person with congenital blindness creates visual images when thinking in concepts as they (the participants) do. This rationalisation can be understood as a defence against the anxiety of the possibility of losing sight by an attempt to negate the differences regarding vision and visualisation between a sighted person and a person with congenital blindness.

Next, the group started questioning the differences in the adjustment processes between a person with congenital blindness and a person with acquired blindness. A person with congenital blindness, the group was saying, can create their world without sight but would never know what seeing is like; they will never have that visual information and reference. On the other hand, a person with acquired blindness could see things and hold images in their minds, making communication more accessible, but recognising the difficulty of losing the ability to see.

At this moment, after recognising the possibility of losing sight and the failed attempt at othering a person with congenital blindness, the group was trying to decide which condition was more challenging: congenital or acquired blindness.

As a resource to mobilise the anxiety, the group started exploring blindness not as a loss but as gaining different abilities, such as improving listening skills. This comment was elicited by the image of a young man with a cane (see Figure 8), suggesting the identification of the participants due to the age gap. This identification allowed the exploration of acquired blindness as something that could (also) happen to young people and could represent not just a loss but acquiring different abilities.

As the participants kept imagining what their experiences would be like if they lost sight, they realised they hadn't thought about the challenges people with blindness face in our society. "People with blindness cannot see the world of sighted people, but, at the same time, sighted people are equally blind to the world of people with blindness, "mentioned one of the participants.

Discussion: a first approach to the perception towards blindness in Mexico

This study explored the perception towards people with blindness by people who are not usually in contact with people with visual impairments.

First, this research showed a general belief that blindness is associated with ageing. This perception is consistent with data from the WHO (2023), which states that, globally, the leading cause of blindness and visual impairments is age-related. Additionally, this study was conducted at a private university. Presumably, both students and their families belong to the middle to high-income status, making preventive eye care affordable and thus minimising the risk of visual impairments. This possibility may explain why the first association towards blindness was related to ageing.

The recognition of the possibility of sight loss was anxiety-provoking for the participants. Extrapolating this reaction to a broader social context, it may explain the othering people with blindness experience by sighted people. This othering may be an attempt to push that possibility as far as possible.

The study also showed a relationship between blindness and death through an association produced by one of the participants: "It is (the gaze) like dead people, but alive". This association implies that sighted people perceive an absence of reflection in the eyes of people with blindness. As mentioned in section 2.3.1, for sighted people, this sense plays a key role in the formation of identity, and it is used throughout life as a mirror that provides a visual recognition and reaffirmation of identity (Lacan, 1969; Winnicott, 1971). If this reflection is not provided, the sighted person can perceive this absence as a resistance from people with blindness to recognise them. Therefore, this association provides evidence of an unconscious resistance of sighted people to recognise people with blindness as a defensive reaction to feeling unrecognised by them. This lack of recognition translates to social barriers placed by sighted people to exclude people with blindness.

People who are not in contact with people with visual impairments are unaware of the social barriers they face. Nonetheless, the association by one of the participants who mentioned that "sighted people are equally blind to the world of people with blindness" shows the possibility for reflexivity and thus opens a possibility towards suspending the need for sighted people to be visually seen to see people with blindness.

Conclusions

The results of this study provided a first approach to exploring the perception towards people with blindness in Mexico. This study sets the baseline for further research to explore the unconscious idea of blindness as a possible explanation for the social barriers created towards people with blindness and visual impairments.

9.2 Pilot study: Exploring the inclusion of psychodynamic psychotherapy in the rehabilitation process for drug addiction.

The following section presents the pilot study conducted in a rehabilitation centre for drug addiction between August and November 2020. The study aimed to explore the perception of drug addiction and the inclusion of psychodynamic psychotherapy in a rehabilitation process in which identity is compromised, such as in the case of drug addiction. Furthermore, the study sought to compare the differences in the perception of drug addiction and sight loss as conditions where identity is compromised and to explore why psychotherapy is provided as a central component of recovery in a rehabilitation process for drug addiction. In contrast, it is non-existent in the rehabilitation process for sight loss. The possible obstacles that the centre for drug addiction faced in implementing this service will be explored to shed light on the potential obstacles present in the rehabilitation centres for blindness.

Incidence and prevalence of drug addiction in Mexico

According to the World Health Organization (2020), substance abuse refers to the dangerous use of psychoactive substances. These substances, including alcohol and illicit drugs, can produce dependence syndrome, a series of behavioural, cognitive, and physiological characteristics that develop after the substance's continuous use. Dependence syndrome includes a strong desire to take the drug, inability to control its use even when facing unhealthy and dangerous consequences, giving the drug a central role in their lives above other activities and obligations, increased tolerance of the substance and withdrawal state when the drug is absent (WHO, 2020).

The Official Report of the Situation of Drug Use in Mexico and its Integral Attention registered that 10.3% of the general population (ages 12 to 65) has used any drug at least once in their lives. The illegal drug that reports the higher use is marijuana

(4.2%), followed by cocaine (3.5%), medical drugs without a prescription (1.3%), amphetamines (0.9%) and opioids (0.2%). The average age of the start of consumption is 17.8 years. Men are registered to have a higher consumption of marijuana (35.2%), followed by alcohol (30.5%), methamphetamines (15%) and tobacco (9.2%), while women are registered to use alcohol (47.1%), marijuana (18.5%) and tobacco (15.2%) (Sánchez et. al., 2019).

The strategy for drug addiction prevention aims to expand the effective access of the population to health services, prioritising vulnerable groups. In July 2017, the National Commission against Addictions (CONADIC) presented the *National Program for the Prevention of the Use, Abuse and Dependence of Psychoactive Substances* (Sánchez et al., 2019). This programme contemplates the development of five strategies:

1. Propel preventive actions to inform, sensitise and educate the population about the risks of using alcohol, tobacco and illicit drugs.
2. Strengthen the early detection, orientation and reference of users of psychoactive substances for the appropriate attention.
3. Promote training for the health care professionals and operatives working in rehabilitation centres to strengthen treatment and rehabilitation services.
4. Strengthen the regulations to detect the harmful use of alcohol and tobacco.
5. Strengthen the epidemiological registration of the consumption of psychoactive substances.

Types of treatments

According to the Official Report of the Situation of Drug Use in Mexico and its Integral Attention, and in agreement with the Official Mexican Norm 028 SSA2-2009 for the prevention, treatment and control of addictions, in Mexico, there are two principal treatment modalities: ambulatory and residential (Sánchez et al., 2019).

Ambulatory services

According to the Official Report of the Situation of Drug Use in Mexico and its Integral Attention, the ambulatory service is represented by the 341 Centres of Primary Attention in Addictions (CAPA), the 104 external consultation services of the Centres of Juvenile Integration (CIJ) and an undetermined number of private clinics. The 447 ambulatory units that depend on the Health Secretary provide medical, psychological and social work attention to people with legal and illegal drug consumption and their families (Sánchez et al., 2019).

The leading ambulatory service throughout the world for drug addiction is the Alcoholic Anonymous groups. Alcoholics Anonymous (AA), also called the Minnesota model or the Abstinence model, is a system created by William Wilson and Robert Smith in 1935 to create a community of people with alcoholism or drug addiction that helped each other stay sober. In AA, the process of sponsorship is that an alcoholic who has made some progress in the recovery program shares their experience on a continuous, individual basis with another alcoholic aiming to maintain sobriety. The sponsor selection is someone with whom the alcoholic seeking sobriety through the program feels comfortable and can talk freely and confidently (Alcoholics Anonymous, 1981). There are more than 14,500 groups in Mexico where people in recovery share their life experiences following the 12 steps and 12 traditions, analyse AA literature, and revise character defects. This mutual help group last for 1.5 hours, and people with drug addiction are requested to participate at least five times a week (Sánchez et. al., 2019).

Residential treatments

According to the Official Report of the Situation of Drug Use in Mexico and its Integral Attention, residential attention is integrated by 11 hospitalisation units of the

Centres of Juvenile Integration (CIJ), 44 public residential units and 2,108 private residential centres (Sánchez et. al., 2019). From the 2,108 private centres, 1,045 are registered, and 348 are recognised as centres that agree with at least 80% of the NOM-028-SSA2-1999 for the prevention, treatment and control of addictions. The type of service offered by residential attention can be classified as follows:

1. Professional establishments: clinics or hospitals that meet the law requirements to have health professionals, detoxification units, permission to prescribe medication, a work programme and accredited professional staff.
2. Mutual help establishments: residential services provided in centres managed by recovery addicts that don't necessarily have an academic formation in the treatment for drug addiction. They usually don't have professional staff, although most receive external support from health professionals when needed.
3. Mixed establishments: these centres combine the health care professional's participation with the experience of recovering addicts with long periods of abstinence.

Of the 44 public residential units, 19 are exclusively for men, two for women and 23 are mixed centres. Regarding the age of attention, five provide attention only to children and adolescents, 22 to a population older than 18, and the remaining 17 to adolescents and adults. The treatment model is formal in 30 units and mixed in 14 The time modality varies from 30 days to 6 months (Sánchez et al., 2019).

The principal therapeutic programmes implemented in the centres are the Minnesota model (AA), therapeutic community and psychological therapy. Mandated by Norm 028 SSA2-2009 for the prevention, treatment and control of addictions, all public and private centres have to follow the same protocol for the psychological treatment for drug addiction. This protocol was adapted by the Psychology Faculty of the National Autonomous University (UNAM). The treatment includes a psychiatric assessment and medication to manage the effect of the intoxication and organic dysfunctions and cognitive behavioural therapy to motivate the patient to increase their compromise to change. Group therapy is provided with three cognitive-behavioural therapeutic models of training: a) transtheoretical change model, b) motivational interview and c) relapse prevention. Family and couples therapy is included in the treatment to improve communication, clarify the dynamics and discover the resources between the family or couple to generate their own change (Sánchez et al., 2019).

Identity and drug addiction

It is not uncommon that the "*toxicomany*" precipitates a conclusive knowledge and cause. According to Le Poulichet (2012), to*xicomany*, as a diagnostic entity, has served as a way of transmitting messages (ideological, moral, political) as the drug elicits a particular social imaginary. It presents the image of intoxication. A person called a "drug addict" is trapped in a definition representing a social scourge and is the object of political law. A set of discourses (scientific, moral, social and juridical) sets them as the "addict". This discourse duplicates in other speeches (the society, neighbourhood, work, home) that have chosen the "addict" to represent a problem.

In 1935 the first efforts to differentiate the phenomenological problem of addiction from the substances' action appeared. Gross (1935) argued that the psychiatrists made the mistake of believing that the only course of therapy was deprivation from the substance and that the patients have come to share this belief.

In opposition to this belief, two tendencies emerged from a psychoanalytical perspective. 1) to identify drug addiction as a variant of a known pathology in a defined personality structure, or 2) to define drug addiction as an autonomous psychopathological organisation (Le Poulichet, 2012).

In the 1950s Durand, a French neurologist, proposed the notion of "encounter", defining that for drug addiction to occur, a specific neurotic organisation had to encounter a substance. Nonetheless, not all drug addicts can be characterised by a unique neurotic structure. The notion of this encounter holds a medical model in which the "disease" is provoked when a substance meets the appropriate host (Le Poulichet, 2012).

From this time, Le Poulichet (2012) explains, *toxicomany* is defined as a physiological dependence duplicated by psychological dependence.

Opposing this theory, Bergeret (1983) defines common traits of a "drug addict" as the difficulty of recognising themselves as a real person, the lack of self-trust, drive regression, or insufficient secondary genitalisation process. He proposes that it is impossible to talk about a structure. He defines a *personality of a drug addict* as immature, indecisive, unsatisfied, and entirely dependent on others. These characteristics, he would argue, make them easy victims of drug addiction.

The *toxicomany* is then presented as an autonomous entity, and the objectives towards the cure are to reconfigure the narcissism and restore the capacity of dialogue.

Le Poulichet (2012) explored that in the XIX century, drug addicts were defined by the drug they consumed as if the toxic substance possessed the person. The personality of the drug was incorporated into the person and became their master. Thus, psychic disturbances are only the effect of toxic processes. The model for understanding *toxicomany* becomes similar to the conception of madness with an involuntary self-intoxication. The interest in the *toxicomanies* increased as they are thought to be able to provide knowledge to understand madness. A differentiation is then established in how drug addiction operates in the frame of psychosis: psychosis following an intoxication or intoxication as a counterflow of the internal toxic substance. The drug becomes a physical supplement to the psychological absence, sometimes a healing agent and other times a poison. In the XVII century, a pharmacologist named Cullen proposed that opium is both a stimulant and a sedative; when it is used, the positive becomes negative. The medication, therefore, creates a double current: the toxic becomes delicious (Le Poulichet, 2012).

In 1970 a new dimension was added to the definition of drug addiction. To the physical and psychological dependence, a socioeconomic and cultural context is defined as "toxic". Drug addiction was then accepted as deviating conduct aligned with a drug-dependent state. The chemical substance is, by all means, the cause of the drug addiction, even if a "toxic society" enforce its effects or if it is established in a "particular personality". A series of explanations were precipitated to create a causality of drug addiction. The loss of values, the absent parents and the violence of socioeconomic evolution were defined as factors that led adolescents to drug addiction. Surprisingly, the social discourse surrounding drug addiction remains unchanged (Le Poulichet, 2012).

The discourses surrounding drug addiction as psychopathology seek to use psychological and psychoanalytical concepts to declare a drug addiction as a personality structure in opposition to a symptom. This objectification reinforces the pathological discourse given to drug addiction, by which the drug addict and their families are captured. This psychological discourse makes *toxicomany* a "theory" to hide the truths of social alienation (Le Poulichet, 2012).

As explained by Earp et al. (2019), the reason for this social alienation is the "moral deterioration" of the values adopted by society. This moral perspective traps a person with drug addiction as either victim of a "brain disease" or as having free will and choosing to consume a drug and act without "morality". The person is defined by their addiction, judged by their "moral actions", and alienated accordingly.

The operation of drug addiction as a narcissistic formation cannot define the structure of a person and has different destinations. Using a drug is a secondary moment of retreat that seeks a remedy for intolerable suffering that cannot be transformed into words. This formation can be completely transitory and has to be referred to what preceded its origin (Le Poulichet, 2012).

Therefore, the treatment of drug addiction is not the separation of the drug as an object but treating the symptom for which the drug is used. This way, the therapist can move from "treating the drug addiction" towards curing the reason for the drug addiction (Le Poulichet, 2012).

By treating drug addiction as a symptom of a more profound problem and not as the problem itself, the person's identity as a drug addict is lifted. This process challenges a society that has placed people with drug addiction in a rejected position, and a system (AA) created to control the urge to use drugs by promoting the people with drug addiction to define themselves as sick and ungovernable, having an uncontrollable disease that only a higher power could help control.

At a personal level, drug addiction impacts identity, such as in the case of sight loss. Socially, people with both conditions, either drug addiction or sight loss, are located in a position of exclusion in society. Taking into consideration both the differences and the similarities between the conditions, the following section presents the research design of the pilot study made in a rehabilitation centre for drug addiction and how this information will be used to address the main study.

Research design

The pilot study aimed to explore the perception of drug addiction and the inclusion of psychodynamic psychotherapy in a rehabilitation process in which identity is compromised. Furthermore, the study seeks to compare the differences in the perception of drug addiction and sight loss as conditions where identity is compromised to explore why psychotherapy is provided as a central component of recovery in a rehabilitation process for drug addiction and non-existent in a rehabilitation process for sight loss.

Sample and methods

This study was conducted at a private drug addiction centre located in Mexico. This centre was selected as it includes psychoanalytic psychotherapy in its rehabilitation model.

This a residential treatment in which the internment lasts for eight months. During those eight months, the patient lives in a therapeutic community that enforces responsibilities and services, works through the Minnesota Model and receives psychoanalytic psychotherapy every week and psychiatric attention every two weeks for medication follow-up. This centre specialises in drug addiction but can provide attention to people with addictions in general (González, 2020).

As the main interest was to explore the perception of psychodynamic psychotherapy in a rehabilitation process in which identity is compromised and the needs and obstacles for implementing this service, the sample was selected for convenience by the researcher as key participants who could address these topics. Two directors were invited to participate as they could provide information about including psychoanalytic psychotherapy in the centre. Additionally, the psychiatrist was invited to explore the perception of psychoanalytic psychotherapy and the multidisciplinary approach to mental health in the rehabilitation process for people with drug addiction.

The interviews were conducted using the Free Association Narrative Interview method (FANI) to practice and replicate the methodology used for the rehabilitation centre staff for blindness. The interviews were conducted in Spanish, transcribed, and translated into English. The data was analysed using narrative and thematic analysis.

Ethical considerations

All participants were at least 18 years old and signed a written informed consent form (see Appendix 9.2.1 and 9.2.2). The interviews were audio-recorded, and all the information was anonymised and stored in a secure, password-protected folder on UWE One Drive that was only accessible to the researcher, the Director of Studies and the Second Supervisor.

In order to triangulate the data and avoid wild analysis, two panels of experts were created to analyse exerts from the interviews. One panel was formed by a Mexican psychoanalyst with experience working with patients with drug addiction and a Spanish neuropsychologist who has been living in Mexico for six years. This first panel provided a psychoanalytic and neurological perspective whilst holding the cultural frame. The second panel was composed of five psychosocial researchers from England who could provide their insight into both the analysis of the material and the methodology.

Results

This section presents the information found through the interviews conducted in the research centre for drug addiction that was later analysed by the panels of experts. The information is presented in sections that correspond to the identified themes. At each section, thoughts about how these results could be incorporated into the main study are included.

Three interviews were conducted, one with each director and one with the psychiatrist. The interviews of the administrative and the clinical coordinator aimed to explore why they created the rehabilitation centre in this particular way, specifically including psychoanalytic psychotherapy, the benefits and challenges they perceive, and to explore their perception between identity and drug addiction. The interview of the psychiatrist, on the other hand, aimed to explore his experience working in the rehabilitation centre and his view on identity and drug addiction.

1.- Formation of the centre

Both directors talked about their personal experiences as recovering addicts as the reason for creating a rehabilitation centre. In their experience, they recognised the beneficial aspects and the limitations that their processes had. Both of them were in residential treatment with closed doors, meaning they couldn't decide to leave. As this is the only model they knew and it worked, they decided to implement the centres as residential, closed-door treatment. Nonetheless, they recognise that not everyone needs to be in residential treatment and that ambulatory services could be helpful. In their experiences, they lived in a therapeutic community with clear responsibilities and severe punishments. They decided to include the therapeutic community and the clear duties but exclude extreme punishments such as the lack of food or sleep. When a rule is broken, the ultimate punishment is to sit in a chair facing the wall whilst reading the AA book. Inside the therapeutic community, they worked through the Minnesota Model. They were assigned a sponsor, but neither received professional help from a psychologist or a psychiatrist. They both coincide in that the AA program and the sponsor have a limit in that support. Each of them, at different times, sought psychoanalytic psychotherapy to help them understand the reason for their addiction and work it through. In the centre that they later created, they included the Minnesota Model as an essential piece of the recovery process. However, they placed the centre of the recovery in psychological treatment, including individual psychoanalytic psychotherapy, psychoanalytic group therapy, family sessions and psychiatric help whenever needed.

First, it's interesting to point out that the idea to create a rehabilitation centre began with their own experiences and wanting to help people in the recovery process of drug addiction in the way they would have liked to get helped themselves. This can shed light on the importance of exploring the reason for creating the rehabilitation centres for blindness in the main study and if the current work made by the centre aligns with the mission upon which they were built.

Another aspect to explore is why the rehabilitation centres for blindness are only ambulatory and if a residential space where the practical and mental health tools are provided inside a community could be an option to support the process of adjustment to sight loss.

The psychiatrist has been working at the centre since the beginning of the project. Since the third year of his psychiatric residency, he has been interested in drug addiction since he rotated in a rehabilitation centre for drug addiction. Afterwards, he decided to pursue a master's programme in Psychoanalysis. He focuses solely on the psychiatric attention of the patients at the centre, leaving the psychoanalytic interventions to the psychologists. He sees patients that need medication once every two weeks, whilst the psychological sessions are once or twice a week, depending on the patient's needs.

Working with people with drug addiction is challenging as it usually entails an underlying psychological condition and a dependence on a substance (Le Pouliche, 2012). The psychiatrist's experience highlights the importance of exploring if the staff members working in the rehabilitation centres for blindness are interested in their work and the population they work with, as it represents critical emotional challenges, i.e. facing the possibility of sight loss themselves. The lack of interest could lead to a lack of recognition of the services' user as a human being and, therefore, to an ableist position (Loja, Costa, Hughes & Menezes, 2012).

2.- Challenges for implementing psychoanalytic psychotherapy in a rehabilitation centre

Both directors discussed the many challenges of implementing psychoanalytic psychotherapy in the rehabilitation centre.

The most significant challenge was that since the creation of the MA programme for drug addiction at the Autonomous University of Mexico. Federal law requires rehabilitation centres to provide cognitive behavioural therapy. The therapist works with the patient on the AA steps. The revision of the implementation of this type of treatment is included in the yearly federal quality assessment to decide if the centre can continue to operate. In a challenging manner, the directors decide to yearly fail in that criteria and fight for what they believe is the right way to treat the patients, separating the therapeutic space from the AA programme. Hence, the patient can have a space to talk about whatever they want and work through what started their addiction. One of them stated: *"I have nothing against it. I know it's useful for some people that arrive at this centre, but I don't believe that the centre would have to pervert their model and way of working to fulfil the norm.*" The psychiatrist comments that *"having psychoanalytic therapists enriches the programme. Working psychoanalytically requires training. Not everyone can do it. A psychoanalyst could handle a patient in a cognitive behavioural oriented therapy but not the other way around."*

Regarding this particular challenge, it will be essential to explore any regulations as to the implementation of psychotherapy in rehabilitation centres for sight loss and, if so, the type of therapy. Additionally, it'll be interesting to explore if the centres for blindness follow any protocol or regulation, and if so, which ones.

The economic factor was also a challenge. One of the directors mentioned that *"in other centres, professional help is only provided for those whose families can* *pay for the service".* Changing this culture and including the payment of psychotherapists in the expenses was complicated.

The rehabilitation centre for drug addiction includes weekly psychotherapy at the monthly cost of the patients, paying the therapists a symbolic fee (250 MXN- £9) per session when the regular payment for a therapist is between 600 and 900 MXN (£21-32) per session. As for the rehabilitation centre for drug addiction, it'll be important to explore if the economic factor can represent a challenge for the implementation of psychotherapy in rehabilitation centres for blindness, and if so, how.

Intertwining the professional help with the AA model was a challenge that required the *"professionalisation of AA counsellors and for them to understand the depth of the therapeutic interventions"* and *"the acceptance and respect from the therapist towards the AA model sponsors".*

This challenge can be relatable in terms of the acceptance and respect from the medical community and sight loss rehabilitators in the centres for blindness. Along with the interviewing process, observation can provide information regarding the acceptance of psychotherapy in the medical community.

Another challenge presented was *"finding therapists that have experience in treating drug abuse. Right now, the group consolidated by the therapists are people who built their experience working at the centre, not from proper training."*

Besides exploring if therapy is provided for people with sight loss in the rehabilitation centres for blindness, it'll be essential to study the therapists' training and experience as it's an important aspect of its usefulness (Thurston et al., 2013).

An ongoing reported challenge is working with the families: *"I wish the treatment can include further and broader aspects of working with the family".*

The inclusion of family work is a crucial aspect to include in the mental health protocols as it's not only the person with sight loss adjusting to their new reality but also the family. It'll be interesting to explore if this type of work is included in the centres for blindness.

The psychiatrist recognises that the centre has developed in mental health attention. Nonetheless, he still perceives a challenge in the psychiatry area: *"I wish someday we could have a proper detoxication area, with nursery and everything needed, but that requires an economic investment along with finding qualified personnel."* Additionally, he addresses the need for research in the centre: *"we've talked about doing formal research, before the pandemic…making interviews, register the diagnosis, epidemiological factors. Simple, but that could let us know the situation we're dealing with."*

Another important aspect to explore is if there are research protocols in the rehabilitation centres for blindness and if they evaluate the impact of professional mental health services.

3.- Self-perception and drug addiction

Regarding self-perception and drug addiction, the opinions started drastically differentiating. One director talked about his experience of not being able to perceive himself: *"When you start being honest, you feel bad because you see what the other people saw in you that you were never able to see. You believed everything was fine."*

The other director refused to talk about a generalisation, stating that *"it's different from case to case. I would say that there might be a common denominator, but that's the point, to understand that every case is different. Even if we could talk about generalities because that's what turns people into specialists now, the devil is in the details".*

He also addressed the social problem of normalising the use of drugs and how the self-perception of a drug addict may depend on the level of social integration: *"In* *some cases, there might be a limitation, in others not. I believe it depends on the level of social integration that wouldn't depend not only on the drugs they use but also on other things. That has changed through time. In the '80s and '90s, perhaps before, people who used drugs felt excluded, and people feared them, but now it's something completely normal."*

The psychiatrist is the only interviewee that is not a recovering addict. The question presented to him was his perception of a person with drug addiction. He responded that he sees a patient with drug addiction as a patient with dual pathology, as a comorbidity between a mental disorder and the drug addiction: *"As a psychiatrist, I try to find the reason for the use of the drug. They're trying to feel or counteract an affect that they're feeling, and I work that first problem for it to be easier not to look for the substance. Medically this is what I do. I understand the psychodynamic aspects, the family, the patient's intrapsychic problems, and their self-capacities. I like working with that, but I don't get involved with these patients. I see the psychiatric aspect."*

When asked how he thinks a patient with a drug addiction perceives themselves, he talks about the patient feeling misunderstood and how to build a trusting relationship to work with them: *"I believe they feel misunderstood and against the world, that no one understands them. We need to start by saying that we understand and explore the reasons that led them to their addictions to start supporting them."*

It's interesting to see that the three of them were answering from their own experiences. One director talks about being honest with himself and seeing something he wasn't able to see before. According to Thurston (2010), recognising sight loss is a crucial aspect of the adjustment process. This relationship is the first indicator that drug addiction and sight loss are not so different regarding the difficulty in accepting the situation and the compromise of identity that acceptance entails.

The other director talks about the problem of normalising drug use and how drug addiction might or might not be a limitation to the person according to their level of social integration. This exclusion is also something people with drug addiction share with people with sight loss. In Mexico, people with sight loss encounter several social barriers that exclude them and make it impossible to perform everyday activities in an individual, autonomous way. Another area to explore in the rehabilitation centres for sight loss is if they have protocols to help people with sight loss reintegrate into society.

It's interesting to note that the psychiatrist is talking about *they.* This might be because of his profession or because he is the only interviewee who is not a recovering addict. Hollway and Jefferson (2008) stated that the defended subject is a central position in which a subject's defences against anxiety are mobilised. The psychiatrist's way of talking could represent a defended subject from the anxiety of the possibility of becoming a person with drug addiction, and hence the necessity of othering the people with drug addiction by positioning himself in a superior dynamic as "the psychiatrist" and placing them as inferior, as "the patients" instead of seeing and talking about them as people. Another crucial aspect to consider when doing the interviews on the rehabilitation centres for blindness is to explore if the staff members are othering the users of the services via a superior-inferior dynamic.

4.- Identity and drug addiction

Both directors share their views about identity and drug addiction. One of them mentioned, *"A drug addict wants to avoid feeling (frustration, fear, and anxiety). To liberate something that cannot be done in sobriety. Everything in their person is exaggerated. Drug addiction expands what was already there, and it's uncontrollable for the addict."* And *"many people start using drugs because they're going through some emotional pain and the substance appears as palliative."*

One of them generalised all the people with drug addiction by saying that *"the addict can't see their own self, they believe they're the most intelligent person in the world, that no one can compete against them, that they're always right, that the drug doesn't control them, that everything's okay, that everyone else is wrong. It's all a lie."* On the other hand, the other director offered a differentiator: *"Many people that had problems with substances in their adolescence ends at 23-24 when the development of the brain finishes, and there's maturity in judgment and decision making, impulse control. In other cases, there's a structure that matches the identity of someone that consumes substances where there's an important narcissistic component, selfishness, and difficulty in dealing with frustration or handling unpleasant emotions. There's usually also the absence of the law or the law mediated by the mother or other figures that don't match the father."*

Interestingly, he proposes this structure after refusing to generalise his previous reply on self-perception and drug addiction. Being a recovering addict, this could suggest that in his earlier answer, he was defending from the anxiety of generalising in a topic that also defines him, along with a reluctance to talk about himself. His definition of a structure is particularly interesting, as it matches the one presented by Sylvie Le Poulichet (2012) when debating drug addiction as a symptom or a personality structure of its own. This could suggest that the therapeutic stand on clinical drug addiction is either a passing event in adolescence or an established personality structure instead of a symptom that could be explored and resolved in therapy.

It will be interesting to explore if the perception of sight loss of both the staff and the rehabilitation centres' users for blindness is seen as a condition that condemns the person or that could be worked through towards its adjustment. Additionally, it'll be interesting to explore if this perception is constructed by unconscious associations and projections and/or social and cultural connections towards blindness.

The psychiatrist addresses identity and drug addiction as a cultural aspect: *"Belonging to a group, being accepted by a group, having the courage to do certain things, I think that's important to the patients, the group with whom they use drugs, gathering to use drugs. The identity they have by belonging to a group that dedicates to consuming or stealing, etc. There's a lack of identity, and they find it inside these groups."*

Belonging to a group can be perceived as an identity. It'll be interesting to explore how the users of the rehabilitation centres for blindness perceive their belonging to "the group" of people having blindness. Additionally, it's important to explore if a therapeutic community exists in the centres.

5.- Perception of society towards drug addiction

Regarding society's perception of drug addiction, one director stated, *"Culturally, a drug addict is the lowest. We can say the value is the same as any other person, and it's like any other disease, but a person with diabetes who eats a cake doesn't get yelled at or expelled from home, and a person with diabetes has more relapses than a drug addict. People see addiction not as a disease but as a choice."* The other director stated that *"it depends on the substance. The situation changes, for example, between alcohol and cocaine in terms of legality or something socially acceptable, addictive potentiality and social integration."*

Both of them believe that the perception changes depending on the person's social integration: *"In the culture in which we grew up, the parents of those who are using drugs right now believed that an alcoholic lives under a bridge. They believed an alcoholic couldn't have a job or family and just have problems during the weekend that the family helps to cover". "If the person is successful and has money, people don't satanise the use of drugs as with someone who doesn't have a job or is having a bad* *time. Even if they might not have a big problem with the substance, that makes the perception pejorative."*

Both also spoke of the lack of an inclusive culture towards people who use drugs: *"There isn't an inclusive culture, a respect for the liberty of other persons. Other countries are leaders in the politics of social representation and the inclusion of people who use drugs, like Switzerland. Germany and Portugal have adopted those models in which the emphasis is not persecutory.*"

Concerning these replies, Le Poulichet (2012) states that a person called a drug addict is trapped in a definition that represents a social scourge. It's not uncommon that a person with drug addiction is seen and defined as with the drug they use and not as a person. The psychoanalyst Lampl addresses this same issue from her own experience of sight loss, stating that people around her were genuinely curious about her physical health. Still, no one seemed interested in how she felt about losing sight (Lampl & Olivier, 1985). It is a crucial aspect to explore in the main study if the staff members working at the rehabilitation centres for blindness define the person for their physical condition or can see the person behind the blindness.

The psychiatrist believes that the perception of society *"is inconsistent because many people use drugs, either legal or illegal, but it's still a tabu in society. People hide their drug problems or being in a rehabilitation centre. They move to another state or country to keep it hidden. There's a lot of tabu for the patients with drug addiction."*

This tabu also points towards the social exclusion that a person with a drug addiction faces when admitting addiction. This can relate to the second stage of the adjustment model proposed by Thurston (2010), in which the person with sight loss tries to hide their condition to avoid the truth of the diagnosis and the changes it entails. It's important to explore if this avoidance is present in the users of the rehabilitation centre for blindness and, if so, if this is because of a personal, psychological reason or if there's also a social component.

6.- Psychoanalysis as a tool in a rehabilitation process in which identity is compromised

When addressing how emotional support is a tool when thinking about a rehabilitation process for drug addiction as a process in which identity is compromised, the answers differ significantly. One director expressed that psychoanalysis holds *"the necessity to remove the mask. People who don't want to let anybody see them cry are stopping their real identity. If your real identity leads you to cry for x situation, it's okay. Before I was in a rehabilitation process, I wouldn't let myself cry because I had to sustain the image of the strong one, and you limit yourself. In the end, that is not your identity but a borrowed one. This is a characteristic of all alcoholics, not letting themselves feel the emotions as they're supposed to be."*

The other director talked about emotional support in a rehabilitation process for drug addiction as *"having the possibility to reframe, to understand their unconscious motivations, understand aspects in a more profound and complex way than just recognising themselves as an addict, as the majority of programs invite them to. Also, to identify and recognise themselves as responsible for their acts and decisions. Psychoanalysis provides the possibility to restructure their lives, relate with others, and understand their own life. The more significant problem is that treating people with addiction is like AA, a system that tends to present itself as religion, as an absolute truth and the only solution. The problem is that the personal history of every person is forgotten or marginalised. In that history, I believe there can be what promises liberation. Many people in AA stop using drugs but start having problems with other things, gambling, eating disorders, sex, porn, etc."*

This difference could evidence of the meaning that psychoanalysis had for each of them in their recovery process. As Freud stated in his work, Mourning and Melancholia (1966), in a grieving process, one knows what is lost but not what was lost in it. Both drug addiction and sight loss entail a series of losses and cannot be reduced to one meaning but could have different interpretations depending on the person. As stated by the other grieving models of sight loss (Allen, 1989; Tuttle & Tuttle, 1996; Hayeems et al., 2005; Thurston, 2010 and Rose, 2011), sight loss is not necessarily about losing sight but the definition that each person gives to sight loss. It'd be essential to consider this when exploring the perception of sight loss and psychotherapy in the rehabilitation centres for blindness and explore if the mental health programmes are aware of avoiding reducing the interventions to the projections of those creating them.

The psychiatrist's perception regarding psychoanalysis as a tool in a rehabilitation process in which identity is compromised is that *"in some cases, it could be useful, not all of them because of the patient's limitations, i.e.cognitive damage. With many patients, we can work psychoanalytically, not through proper psychoanalysis. Still, our formation allows us to work cognitively, and if we see something deeper, we'll take the chance to intervene. So yes, but with modifications to the technique. Not a psychoanalysis per se, but psychoanalytic therapy, psychodynamic."*

The challenge perceived by the psychiatrist addresses the difficulty of working psychoanalysis with a person with a drug addiction that could be cognitively impaired. Although it can potentially be less common for a person with sight loss to be cognitively impaired, it's important to explore the necessities of both the centres and the users of the services when thinking about emotional support to consider when adjusting or creating mental health protocols.

7.- Challenges of psychoanalytic psychotherapy in a rehabilitation centre

The perceived challenges of psychoanalysis in a rehabilitation centre were also different. One of them talked about the obstacles inside the centre: *"The problem is that the patient sees the therapist as a contact with the exterior, as someone they can talk to who can help them in their way. Then they realise this is not the case. Many patients lose time instead of seeing psychotherapy as a tool to work further in what they're already working with inside the centre."*

Also, he addressed a challenge he perceives from the patients' capacity regarding self-exploration: *"You can see the impact but not in the way we would like. Some people don't have resources. Psychoanalysis is not for everyone; we provide cognitive behavioural therapy and psychoanalysis. I believe psychoanalysis to be more effective, but this will depend on the tools each patient has to work with. Some people can use the space, and others can't, not because the therapist is failing, but because of the lack of tools of the patient."*

The psychiatrist also shared this view, adding that *"changing is hard because they return to their houses, their neighbourhoods. Often, we encounter the difficulty that the parents or the family also use drugs. So the patient returns to that place where they finally believe they belong. If the treatment were ideal, we would think that the family understands the problem, that it's necessary to move to another place psychologically, and that would be very difficult in a country like the one we live in."*

These responses address the personal and social limitations of psychoanalytic psychotherapy in a rehabilitation centre. It's essential to explore if and how emotional support is provided and the theoretical/ research frame from which it was constructed. Additionally, it endorses the importance of including working with the family members and addressing the social perception of blindness to create a community, inside and outside the rehabilitation centre, where people with blindness are not excluded.

Conclusions

Many similarities were found between drug addiction and sight loss. At a psychological level, both conditions compromise identity as they represent a profound change in self-definition. Socially, both conditions are perceived with an ableist view: people with sight loss are constantly excluded by society's physical barriers, and people with drug addiction are perceived as "wanting" to use drugs and "be sick".

Exploring how this centre has been dealing with the difficulties faced in the rehabilitation process of a condition that compromises identity and that requires a re-insertion in society, specifically regarding the inclusion of emotional support, helped me shed light over possible challenges that could be encountered in the rehabilitation centres for blindness and provided insight for questions and themes that I have not considered for the main study.

The pilot study also provided the opportunity to explore the FANI method. Even though I felt comfortable with the method itself as it is similar to my everyday work as a psychoanalyst, that same reason represented a challenge to me as, as stated before, I needed to keep in mind that it was not a psychoanalytic session and to question myself as to when to keep digging further for research purpose.

Hollway and Jefferson (2008) stated that being the researcher also entails being a defended subject in this methodology. Through the pilot study, I interviewed my bosses from the rehabilitation centre for drug addiction. I could recognise my defences against the anxiety of my bosses finding the pilot study and the questions I was asking them "smart enough" for them to believe that I am a good asset to keep employing. I was aware that the power dynamic could affect both the questions and the answers of the study. Since the main project is thought to be the starting point to address the gaps in the rehabilitation and inclusion for people with sight loss, and I have an interest in continuing my relationship with the centres, this was a crucial insight as it allowed me to be aware of the power dynamics that might come at play through the interviews.

9.2.1: Consent form for staff of rehabilitation centres for drug addiction in English

Participant Information sheet:

Pilot Study: Exploring the inclusion of psychodynamic psychotherapy in the rehabilitation process for drug addiction.

My name is Leslie Thompson and I am a post-graduate researcher at the University of the West of England. I am conducting a project that aims to explore the perception of blindness and the needs and obstacles of the access to psychotherapy in the rehabilitation centres for blindness in Nuevo Leon, Mexico. As part of this project, a pilot study is conduced to explore the access to psychotherapy in a rehabilitation process where identity is compromised, as is the case with blindness. This study aims to explore the access and benefits of psychotherapy in the rehabilitation process of drug addiction, where identity is also compromised, and how this compares to the difficulties in the access to psychotherapy in the rehabilitation centre for blindness.

As you are a member of staff working in a rehabilitation centre for drug addiction where psychodynamic psychotherapy is included as part of the rehabilitation model I would like to invite you to take part in this study. Before you decide, please read the information below carefully. If you have any further questions after reading this, please feel free to talk to me directly or to contact me (details below).

A summary of the study

In Mexico, the official report of 2019 registered that 10.3% of the general population (ages 12 to 65) had use any drug at least once in their lives. The rehabilitation process implemented in this country includes ambulatory and residential modalities. The ambulatory service is represented by the more than 14,500 Alcoholics Anonymous groups, 341 Centres of Primary Attention in Addictions (CAPA), the 104 external consultation services of the Centres of Juvenile Integration (CIJ) and an undetermined number of private clinics. The 447 ambulatory units that depend of the Health Secretary provide medical, psychological and social work attention to people with consumption of legal and illegal drug consumption and their families. The residential treatment is represented by 348 centres that are in agreement with at least 80% of the NOM-028-SSA2-1999 for the prevention, treatment and control of addictions. The principal therapeutic programmes implemented in the centres are the Minnesota model (AA), therapeutic community and psychological therapy.

Mandated by the Norm 028 SSA2-2009 for the prevention, treatment and control of addictions, all public and private centres have to follow the same protocol for the psychological treatment for drug addiction. This protocol was adapted by the Psychology Faculty of the National Autonomous University (UNAM). The treatment includes a psychiatric assessment and medication to manage the effect of the intoxication and organic dysfunctions, and cognitive behavioural therapy to motivate the patient to increase their compromise to change. Group therapy is provided with 3 cognitive-behavioural therapeutic models of training: a) transtheoretical model of change; b) motivational interview and c) relapse prevention. Family and couples' therapy is included in the treatment to improve communication, clarify the dynamics and discover the resources between the family or couple to generate their own change. The purpose of this pilot study is to explore the perception of psychotherapy and the access to a psychodynamic psychotherapy in a rehabilitation centre for drug addiction. This pilot study is part of a broader project that aims to explore the perception of blindness and the needs and obstacles for implementing psychotherapy in the rehabilitation centres of Nuevo Leon, Mexico.

If you agree to take part in the study, you'll be asked to participate in 1 or 2 interviews using the Free Association Narrative Interview method.

Ethics

The study has received ethical approval from the Faculty of Health and Social Science at the University of the West of England.

The project is being supervised by Dr. Lita Crociani- Windland who can be contacted at lita.crociani-windland@uwe.ac.uk should further detail be needed of our ethical processes and procedures.

Data will be treated as confidential and stored securely. All participants details be anonymised.

Why have I been asked?

You have been selected to participate in this study as you are a member of staff of a rehabilitation centre for drug addiction and your experience is a valuable contribution to this project as it allows the exploration of the perception of drug addiction as a change in identity and the access to psychotherapy in a rehabilitation process.

What do I have to do if I agree to take part?

If you decide to take part in the study, you'll be asked to participate in one or two interviews using the Free Association Narrative Interview method, which is a semi-structured interview on which the researcher will present some questions and ask you to associate freely what comes to your mind.

Please complete and sign the consent form that is attached and return it to me before the activity. Each interview will last about 60 minutes and will be conducted in a mutually agreed and appropriate location. With your consent, the interviews will be recorded but the recording will be destroyed when the research has ended.

And if I don't?

You can decide not to take part from the study at any time without any consequences. If you would like to withdraw your information, please request this before November 2020. You are under no obligation to give a reason for not taking part of the study or withdrawing your data.

Are there any possible disadvantages to taking part?

You will be asked to free associate about the questions provided, if any question causes distress the researcher is a licenced psychologist that can provide containment and further reference. If there’s information that the researcher feels the need to disclose this will be discussed with you before disclosure.

Are there any possible benefits

It is hoped this study will help create an understanding of the perception of drug addiction as a change in identity and the access to psychodynamic psychotherapy in its rehabilitation process. By exploring this process, the pilot study aims to shed light over the obstacles for implementing psychodynamic psychotherapy in a rehabilitation centre for blindness, where identity is also compromised.

What will happen to the results of the study?

The results will be included in my final year dissertation, submitted on April 2023. With your consent, this data will used in later research. Further dissemination including conference presentations and publications will not address specific responses of participants.

CONSENT FORM

Full title of project: Pilot Study: Exploring the inclusion of psychodynamic psychotherapy in the rehabilitation process for drug addiction.

Name and contact details of researcher: Leslie Marian Thompson García, M.Sc.
Phone number: +52 (81) 20 01 77 18
Email: leslie2.thompson@live.uwe.ac.uk

…………………………………………………………………………………………….

- I confirm that I have read and understood this information sheet and have had an opportunity to ask questions
- I am aware that I can contact you or your supervisor to discuss any aspect of this interview before taking part, during the research or after the activity
- I am aware that I can decide not to participate or abandon the interview at any time.
- I am aware that if I want to withdraw my information I would need to do so before December 2020
- I consent to the interviews being audio recorded.
- I consent to taking part in this study
- I agree to the use of anonymised quotes in the written-up dissertation
- I agree to the use of this data in later research

Participant contact details

Your Name………………………………………………………………………….…….

Signature……………………………………………………………….…………..…

Date.…………………………………………………………………..…..…...…

Telephone number…………………………………………………..………..…...

Email.…………………………………………………………………..……...

Appendix 9.2.2: Consent form for staff of rehabilitation centres for drug addiction in Spanish

Información para el participante

Título de la Investigación: Explorando el acceso a la psicoterapia psicodinámica en el proceso de rehabilitación de toxicomanías.

Mi nombre es Leslie Thompson, soy una investigadora de posgrado en la Universidad del Oeste de Inglaterra (*University of the West of England*). Actualmente estoy trabajando en un proyecto que explora la percepción que se tiene de la invidencia en los centros de rehabilitación a la invidencia en Nuevo León, México. Como parte de este proyecto, un estudio piloto se llevará a cabo para explorar el acceso a la psicoterapia en un proceso de rehabilitación en el que la identidad se ve comprometida, como es el caso de la invidencia. Este estudio busca explorar el acceso y beneficios de la psicoterapia en un proceso de rehabilitación para la toxicomanía, en el cual la identidad se ve de igual manera comprometida, y cómo esto se compara con las dificultades en el acceso a un proceso terapéutico en los centros de rehabilitación para la ceguera.
En tanto usted es un profesionista que trabaja en un centro de rehabilitación a la invidencia quisiera extenderle una invitación a formar parte de este proyecto. Antes de decidir sobre su participación, le pido leer cuidadosamente la información descrita a continuación. Si, posteriormente, usted tiene alguna pregunta, le pido me contacte directamente a través de los datos proporcionados más adelante.

Resumen del estudio

En México, el reporte oficial del 2019 registró que 103% de la población general (12 a 65 años) había consumido alguna sustancia al menos una vez en sus vidas. En este país, un proceso de rehabilitación incluye servicios ambulatorios y residenciales. El servicio ambulatorio está representado por más de 14,500 grupos de Alcohólicos Anónimos, 341 centros CAPA, 104 centros de consulta externa CIJ y un número no reconocido de clínicas privados. Las 447 unidades ambulatorias que dependen de la Secretaría de Salud provén atención médica, psicológica y trabajo social a personas con consume de drogas legales e ilegales y a sus familias. El tratamiento residencial está representado por 348 centros que se encuentran cumpliendo con al menos 80% de la NOM-028-SSA2-1999 para la prevención, tratamiento y control de adicciones prevención. Los principales modelos terapéuticos implementados en los centros son en Modelo Minnesota (AA), la comunidad terapéutica y psicoterapia.
En seguimiento a la NOM-028-SSA2-1999 para la prevención, tratamiento y control de adicciones, a todos los centros públicos y privados se les solicita se adhieran al mismo protocolo. Este protocolo fue adaptado por la Facultad de Psicología de la Universidad Autónoma de Mexica (UNAM). El tratamiento incluye una evaluación psiquiátrica y medicamento para manejar los efectos de la intoxicación y disfunción orgánica, y

terapia cognitivo conductual para motivar al paciente a incrementar su compromiso de cambio. Se ofrece también terapia grupal con 3 modelos de entrenamiento cognitivo conductual: a) modelo de cambio transteórico; b= entrevista motivacional y c) prevención de recaídas. La terapia familiar y de pareja se incluye en el tratamiento para mejorar la comunicación, clarificar las dinámicas y descubrir los recursos entre la familia o el paciente de generar un cambio.

El propósito de este estudio piloto es explorar la percepción de la psicoterapia y el acceso a la psicoterapia psicodinámica en un centro de rehabilitación para toxicomanías. Este estudio piloto es parte de un Proyecto macro que busca explorar la percepción de la ceguera y las necesidades y obstáculos para implementar un proceso psicoterapéutico en los centros de rehabilitación para la ceguera en Nuevo León, México.

So usted decide formar parte de este estudio se le invitará a participar en 1 o 2 entrevistas utilizando la Entrevista Narrativa de Asociación Libre (*Free Association Narrative Interview method*)

Consideraciones éticas

Este estudio ha recibido aprobación para realizarse por parte del Comité de Ética de la Facultad de Salud y Ciencias Sociales de la Universidad del Oeste de Inglaterra (*University of the West of England*). El proyecto está siendo supervisado por la Dra. Lita Crociani- Windland, quien puede ser contactada a través del correo lita.crociani-windland@uwe.ac.uk si se requiere mayor detalle respecto de los procedimientos éticos de este estudio.

En el reporte final, usted no será identificado, todos los participantes, y su información, será anónima.

Selección de participantes

Usted ha sido seleccionado para participar por ser parte del equipo de profesionales trabajando en un centro de rehabilitación para el abuso de sustancias. Su experiencia es una valiosa contribución para este proyecto ya que permite explorar la percepción de la drogadicción en tanto un cambio en la identidad y el acceso a la psicoterapia en este proceso de rehabilitación.

¿Qué tengo que hacer si decido participar?

Si usted decide ser parte del estudio, se le pedirá que participe en 1 o 2 entrevistas utilizando el método de Entrevista Narrativa de Asociación Libre (*Free Association Narrative Interview),* la cual es una entrevista semi-estructurada en la que el investigador presenta una serie de preguntas y se le pide que asocie libremente sobre la respuesta.

En caso de decidir participar le pido complete y firme el consentimiento informado adjunto a este documento y me lo proporcione antes de la actividad. Cada entrevista tendrá una duración de aproximadamente 60 minutos y se llevará a cabo en un tiempo y espacio acordado. Con su consentimiento, la actividad será audio-grabada y las grabaciones destruidas al término del proyecto.

¿Y si decido no participar?

Usted puede decidir no participar en el estudio, o abandonar la entrevista en cualquier momento. Si usted desea retirar sus datos de la investigación, puede hacerlo antes de Noviembre del año 2020. Usted no tiene ninguna obligación de dar razones por las cuales decide no participar en la investigación o retirar su información.

¿Hay posibles riesgos de participar?

Se le solicitará que asocie libremente sobre temas relacionados a la invidencia, es posible que hablar de estos temas puede causar ansiedad. La investigadora es una terapeuta con licencia capaz de proveer contención emocional y referencia terapéutica en caso de ser necesario. Si hay información en la cual la investigadora considere necesario romper la confidencialidad, esto será discutido con usted personalmente en un momento posterior a la actividad.

¿Hay posibles beneficios de participar?

Se espera que este estudio ayude a crear un entendimiento sobre la adicción en tanto cambio de identidad y el acceso a la psicoterapia psicodinámica en este proceso de rehabilitación. Al explorar esto, este estudio piloto busca evidenciar los obstáculos del acceso a atención psicológica psicodinámica en los centros de rehabilitación para la invidencia, proceso en el que la identidad se encuentra de igual manera comprometida.

Uso de los datos

Los resultados de este estudio serán incluidos en la disertación final, con fecha en Agosto 2022. Con su autorización, estos datos serán incluidos en investigaciones posteriores. Diseminación adicional incluyendo presentaciones en congreso y publicaciones no mencionarán respuestas específicas de los participantes.

CONSENTIMIENTO INFORMADO

Título del Proyecto: Estudio piloto: Explorando el acceso a la psicoterapia psicodinámica en el proceso de rehabilitación de toxicomanías.

Datos de contacto de la investigadora: Leslie Marian Thompson García, M.Sc.
Teléfono: +52 (81) 20 01 77 18
Email: leslie2.thompson@live.uwe.ac.uk

……………………………………………………………………………………………….

- ○ He leído y entiendo la información proporcionada por el documento anterior y he tenido la oportunidad de hacer preguntas.
- ○ Entiendo que puedo contactar a la investigadora o la supervisora del proyecto para discutir cualquier aspecto de la actividad antes, durante o después de participar en ella.
- ○ Entiendo que puedo retirarme del estudio en cualquier momento sin consecuencia alguna.
- ○ Estoy de acuerdo con que si deseo retirar mi información del estudio debo hacerlo antes de Noviembre 2020
- ○ Estoy de acuerdo con que la actividad será audio-grabada.
- ○ Doy mi consentimiento para participar en las entrevistas
- ○ Estoy de acuerdo en que se utilicen notas anónimas de esta actividad en la tesis escrita para la obtención del grado Doctoral en Estudios Psico-Sociales de la investigadora.
- ○ Estoy de acuerdo con que los datos de este estudio se utilicen en proyectos de investigación posteriores.

Información de contacto

Nombre…………………………………………………………………….…………..

Firma……………………………………………………………….…………….…….

Fecha.……………………………………………………………………..…………

Número telefónico…………………………………………………….……………

Correo……………………………………………………………………..…………

9.3 Ethics clearance from the University of the West of England

UWE Bristol
University of the West of England

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.20.01.096

12th March 2020

Leslie Thompson
Leslie2.Thompson@live.uwe.ac.uk

Dear Leslie

Application title: Needs and Obstacles for Implementing Psychotherapeutic Treatment in Acquired Blindness: a Psycho-Social Study

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 11th February 2020 and the study has been given ethical approval to proceed.

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee. Amendments should be requested using the form at http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx

2. You must notify the Research Ethics Sub-Committee if you terminate your research before completion;

3. You must notify the Research Ethics Sub-Committee if there are any serious events or developments in the research that have an ethical dimension.

The Faculty and Research Ethics Sub-Committees (FRECs and RESC) are here to advise researchers on the ethical conduct of research projects and to approve projects that meet UWE's ethical standards. Please note that we are unable to give advice in relation to legal issues, including health and safety, privacy or data protection

9.4 Informed consent forms of main study

Consent form for staff of rehabilitation centres for blindness in English

Participant Information sheet:

Research title: The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

My name is Leslie Thompson and I am a post-graduate researcher at the University of the West of England. I am conducting a project that aims to explore the perception of blindness in the rehabilitation centres for blindness in Nuevo Leon, Mexico.
As you are a stakeholder/ administrative staff/ psychiatrist or psychologist working in a rehabilitation centre for blindness I would like to invite you to take part in this study. Before you decide, please read the information below carefully. If you have any further questions after reading this, please feel free to talk to me directly or to contact me (details below).

A summary of the study

The global efforts destined to the prevention, treatment and rehabilitation of blindness have reduced the global rates of visual impairment since 1995, when visual problems became an official part of the recurring agenda of the World Health Organization's meetings (WHO, 2019). Nonetheless, once blindness is established, the services offered for the people with blindness towards adjusting to this condition seems to focus in providing the access medical attention, access to education and providing instrumental tools. Without minimizing the importance of these resources, the access to emotional support seems to be limited, only provided by few organizations in specific countries. The purpose of this project is to explore the perception of blindness and emotional support in the rehabilitation centres for blindness in Mexico. If you agree to take part in the study, you'll be asked to participate in 1 or 2 interviews using the Free Association Narrative Interview method.

Ethics

The study has received ethical approval from the Faculty of Health and Social Science at the University of the West of England.
The project is being supervised by Dr. Lita Crociani- Windland who can be contacted at lita.crociani-windland@uwe.ac.uk should further detail be needed of our ethical processes and procedures.
Data will be treated as confidential and stored securely. All participants details be anonymised.

Why have I been asked?

You have been selected to participate in this study as you are a professional staff of a rehabilitation centre for blindness and your experience working with people with blindness is a valuable contribution to this project as it allows the exploration of the perception of blindness and emotional support for people with sight loss.

What do I have to do if I agree to take part?

If you decide to take part in the study, you'll be asked to participate in one or two interviews using the Free Association Narrative Interview method, which is a semi-structured interview on which the researcher will present some questions and ask you to associate freely what comes to your mind.
Please complete and sign the consent form that is attached and return it to me before the activity. Each interview will last about 60 minutes and will be conducted in a mutually agreed and appropriate location. With your consent, the interviews will be recorded but the recording will be destroyed when the research has ended.

And if I don't?

You can decide not to take part from the study at any time without any consequences. If you would like to withdraw your information, please request this before January 2022. You are under no obligation to give a reason for not taking part of the study or withdrawing your data.

Are there any possible disadvantages to taking part?

You will be asked to free associate about the questions provided, if any question causes distress the researcher is a licenced psychologist that can provide containment and further reference. If there's information that the researcher feels the need to disclose this will be discussed with you before disclosure.

Are there any possible benefits

It is hoped this study will help create an understanding of the perception of blindness and emotional support in the rehabilitation centres for blindness, with the aim of creating access to psycho-social tools that can facilitate the adjustment process to sight loss.

What will happen to the results of the study?

The results will be included in my final year dissertation, submitted on June 2023. With your consent, this data will be included used in later research. Further dissemination including conference presentations and publications will not address specific responses of participants.

CONSENT FORM

Full title of project: The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

Name and contact details of researcher: Leslie Marian Thompson García, M.Sc.
Phone number: +52 (81) 20 01 77 18
Email: leslie2.thompson@live.uwe.ac.uk

……………………………………………………………………………………………

- ○ I confirm that I have read and understood this information sheet and have had an opportunity to ask questions
- ○ I am aware that I can contact you or your supervisor to discuss any aspect of this interview before taking part, during the research or after the activity
- ○ I am aware that I can decide not to participate or abandon the interview at any time.
- ○ I am aware that if I want to withdraw my information I would need to do so before January 2022
- ○ I consent to the interviews being audio recorded.
- ○ I consent to taking part in this study
- ○ I agree to the use of anonymised quotes in the written-up dissertation
- ○ I agree to the use of this data in later research

Participant contact details

Your Name……………………………………………………………………….……..

Signature………………………………………………………….……….………..…

Date.…………………………………………………………………..…...…...…..…

Telephone number……………………………………………..………..……..……

Email.…………………………………………………………………..…………

Consent form for staff of rehabilitation centres for blindness in Spanish

Información para el participante

Título de la Investigación: La percepción de la ceguera y su impacto en la implementación de apoyo emocional para la pérdida visual en México: un Estudio Psico-Social.

The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

Mi nombre es Leslie Thompson, soy una investigadora de posgrado en la Universidad del Oeste de Inglaterra (*University of the West of England*). Actualmente estoy trabajando en un proyecto que explora la percepción que se tiene de la invidencia en los centros de rehabilitación a la invidencia en Nuevo León, México.
En tanto usted es un profesionista que trabaja en un centro de rehabilitación a la invidencia quisiera extenderle una invitación a formar parte de este proyecto. Antes de decidir sobre su participación, le pido leer cuidadosamente la información descrita a continuación. Si, posteriormente, usted tiene alguna pregunta, le pido me contacte directamente a través de los datos proporcionados más adelante.

Resumen del estudio

Los esfuerzos mundiales destinados a prevención, tratamiento y rehabilitación de la invidencia han reducido los problemas visuales desde 1995, fecha en la cual este tema fue incluido en la agenda de las reuniones de la Organización Mundial de la Salud. Sin embargo, una vez que existe ceguera, los servicios ofrecidos para las personas con ceguera se enfocan en el acceso a atención médica, acceso a la educación y cursos para el desarrollo de habilidades instrumentales. Sin minimizar la importancia de estos recursos, el acceso a apoyo emocional parece limitado, solamente ofrecido por pocas organizaciones en países específicos. El propósito de este proyecto es explorar la percepción de la invidencia y el apoyo emotional en los centros de rehabilitación a la invidencia en México. Si usted está de acuerdo en formar parte del estudio, se le solicitará participar en 1 o 2 entrevistas utilizando el método Psico-Social llamado Entrevista Narrativa de Asociación Libre (*Free Association Narrative Interview)*

Ética

Este estudio ha recibido aprobación para realizarse por parte del Comité de Ética de la Facultad de Salud y Ciencias Sociales de la Universidad del Oeste de Inglaterra (*University of the West of England*). El proyecto está siendo supervisado por la Dra. Lita Crociani- Windland, quien puede ser contactada a través del correo lita.crociani-windland@uwe.ac.uk si se requiere mayor detalle respecto de los procedimientos éticos de este estudio.

En el reporte final, usted no será identificado, todos los participantes, y su información, será anónima.

Selección de participantes

Usted ha sido seleccionado para participar por ser parte del equipo de profesionales trabajando en un centro de rehabilitación para la invidencia. Su experiencia trabajando con personas con invidentes es una valiosa contribución para este proyecto ya que permite explorar la percepción de la ceguera y apoyo emocional para personas que pierden la vista.

¿Qué tengo que hacer si decido participar?

Si usted decide ser parte del estudio, se le pedirá que participe en 1 o 2 entrevistas utilizando el método de Entrevista Narrativa de Asociación Libre (*Free Association Narrative Interview),* la cual es una entrevista semi estructurada en la que el investigador presenta una serie de preguntas y se le pide que asocie libremente sobre la respuesta.

En caso de decidir participar le pido complete y firme el consentimiento informado adjunto a este documento y me lo proporcione antes de la actividad. Cada entrevista tendrá una duración de aproximadamente 60 minutos y se llevará a cabo en un tiempo y espacio acordado. Con su consentimiento, la actividad será audio-grabada y las grabaciones destruidas al término del proyecto.

¿Y si decido no participar?

Usted puede decidir no participar en el estudio, o abandonar la entrevista en cualquier momento. Si usted desea retirar sus datos de la investigación, puede hacerlo antes de Enero 2022. Usted no tiene ninguna obligación de dar razones por las cuales decide no participar en la investigación o retirar su información.

¿Hay posibles riesgos de participar?

Se le solicitará que asocie libremente sobre temas relacionados a la ceguera, es posible que hablar de estos temas puede causar ansiedad. La investigadora es una terapeuta con licencia capaz de proveer contención emocional y referencia terapéutica en caso de ser necesario. Si hay información en la cual la investigadora considere necesario romper la confidencialidad, esto será discutido con usted personalmente en un momento posterior a la actividad.

¿Hay posibles beneficios de participar?

Se espera que este estudio ayude a crear un entendimiento sobre la percepción que se tiene hacia la ceguera y apoyo emocional en los centros de rehabilitación con el fin de crear herramientas psico-sociales que puedan facilitar la adaptación a la ceguera de una persona con pérdida visual

Uso de los datos

Los resultados de este estudio serán incluidos en la disertación final, con fecha en Octubre 2023. Con su autorización, estos datos serán incluidos en investigaciones posteriores. Diseminación adicional incluyendo presentaciones en congreso y publicaciones no mencionarán respuestas específicas de los participantes.

CONSENTIMIENTO INFORMADO

Título del Proyecto: La percepción de la ceguera y su impacto en la implementación de apoyo emocional para la pérdida visual en México: un Estudio Psico-Social.

The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

Datos de contacto de la investigadora: Leslie Marian Thompson García, M.Sc.
Teléfono: +52 (81) 20 01 77 18
Email: leslie2.thompson@live.uwe.ac.uk

…………………………………………………………………………………………….

- ○ He leído y entiendo la información proporcionada por el documento anterior y he tenido la oportunidad de hacer preguntas.
- ○ Entiendo que puedo contactar a la investigadora o la supervisora del proyecto para discutir cualquier aspecto de la actividad antes, durante o después de participar en ella.
- ○ Entiendo que puedo retirarme del estudio en cualquier momento sin consecuencia alguna.
- ○ Estoy de acuerdo con que si deseo retirar mi información del estudio debo hacerlo antes de Enero 2022
- ○ Estoy de acuerdo con que la actividad será audio-grabada.
- ○ Doy mi consentimiento para participar en las entrevistas
- ○ Estoy de acuerdo en que se utilicen notas anónimas de esta actividad en la tesis escrita para la obtención del grado Doctoral en Estudios Psico-Sociales de la investigadora.
- ○ Estoy de acuerdo con que los datos de este estudio se utilicen en proyectos de investigación posteriores.

Información de contacto

Nombre……………………………………………………………………………..

Firma…………………………………………………………………………………

Fecha……………………………………………………………………………….

Número telefónico………………………………………………………………….

Correo………………………………………………………………………………

Consent form for users of rehabilitation centres for blindness staff in English

Participant Information sheet:

Research title: The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

My name is Leslie Thompson and I am a post-graduate researcher at the University of the West of England. I am conducting a project that aims to explore the perception of blindness in rehabilitation centres for blindness using a psycho-social interview method known as the Biographical Narrative Interview Method.
As you are a user of the services of a rehabilitation centre for blindness I would like to invite you to take part in this study. Before you decide, please listen to the information below carefully. If you have any further questions after reading this, please feel free to talk to me directly or to contact me (details below).

A summary of the study

The global efforts destined to the prevention, treatment and rehabilitation of blindness have reduced the global rates of visual impairment since 1995, when visual problems became an official part of the recurring agenda of the World Health Organization's meetings (WHO, 2019). Nonetheless, once blindness is established, the services offered for the people with blindness towards adjusting to this condition seems to focus in providing the access medical attention, access to education and providing instrumental tools. Without minimizing the importance of these resources, the access to emotional support seems to be limited, only provided by few organizations in specific countries. The purpose of this project is to explore the perception of blindness and emotional support in the rehabilitation centres for blindness in Mexico. If you agree to take part in the study, you'll be asked to participate in 1 or 2 interviews using the Biographic-Narrative Interpretative Method.

Ethics

The study has received ethical approval from the Faculty of Health and Social Science at the University of the West of England.
The project is being supervised by Dr. Lita Crociani- Windland who can be contacted at lita.crociani-windland@uwe.ac.uk should further detail be needed of our ethical processes and procedures.
Data will be treated as confidential and stored securely. All participants details be anonymised.

Why have I been asked?

You have been selected to participate in this study as you are a user of the services of a rehabilitation centre for blindness and your experience is a valuable contribution to this project as it allows the exploration of the perception of blindness.

What do I have to do if I agree to take part?

If you decide to take part in the study, you'll be asked to participate in one or two interviews using the Biographic-Narrative Interpretative Method, on which you will be asked a biographical recount of your experience with blindness.
Please complete and sign the consent form that is attached and return it to me before the activity. Each interview will last about 60 minutes and will be conducted in a mutually agreed and appropriate location. With your consent, the interviews will be recorded but the recording will be destroyed when the research has ended.

And if I don't?

You can decide not to take part from the study at any time without any consequences. If you would like to withdraw your information, please request this before January 2022. You are under no obligation to give a reason for not taking part of the study or withdrawing your data.

Are there any possible disadvantages to taking part?

You will be asked to free associate about your experience with blindness, if any question causes distress the researcher is a licenced psychologist that can provide containment and further reference. If there's information that the researcher feels the need to disclose this will be discussed with you before disclosure.

Are there any possible benefits

It is hoped this study will help create an understanding of the perception of blindness and emotional support in the rehabilitation centres for blindness, with the aim of creating psycho-social tools that can facilitate the adjustment process of a person with acquired blindness.

What will happen to the results of the study?

The results will be included in my final year dissertation, submitted on June 2023. With your consent, this data will be included used in later research. Further dissemination including conference presentations and publications will not address specific responses of participants.

CONSENT FORM

Full title of project: The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

Name and contact details of researcher: Leslie Marian Thompson García, M.Sc.
Phone number: +52 (81) 20 01 77 18
Email: leslie2.thompson@live.uwe.ac.uk

…………………………………………………………………………………………

Participant confirmation and contact details will be audio recorded.

- ○ I confirm that I have read and understood this information sheet and have had an opportunity to ask questions
- ○ I am aware that I can contact you or your supervisor to discuss any aspect of this interview before taking part, during the research or after the activity
- ○ I am aware that I can decide not to participate or abandon the interview at any time.
- ○ I am aware that if I want to withdraw my information I would need to do so before January 2022
- ○ I consent to the interviews being audio recorded.
- ○ I consent to taking part in this study
- ○ I agree to the use of anonymised quotes in the written-up dissertation
- ○ I agree to the use of this data in later research

Participant contact details

Your Name………………………………………………………………………………..

Signature……………………………………………………………………………….

Date.……………………………………………………………………………………...

Telephone number……………………………………………………………………….

Email……………………………………………………………………………………….

Consent form for users of rehabilitation centres for blindness in Spanish

Información para el participante

Título de la Investigación: La percepción de la ceguera y su impacto en la implementación de apoyo emocional para la pérdida visual en México: un Estudio Psico-Social.

The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

Mi nombre es Leslie Thompson, soy una investigadora de posgrado en la Universidad del Oeste de Inglaterra (*University of the West of England*). Actualmente estoy trabajando en un proyecto que explora la percepción que se tiene de la invidencia en los centros de rehabilitación a la invidencia en Nuevo León, México.
En tanto usted es un usuario de los servicios un centro de rehabilitación a la ceguera quisiera extenderle una invitación a formar parte de este proyecto. Antes de decidir sobre su participación, le pido escuchar cuidadosamente la información descrita a continuación. Si, posteriormente, usted tiene alguna pregunta, le pido me contacte directamente a través de los datos proporcionados más adelante.

Resumen del estudio

Los esfuerzos mundiales destinados a prevención, tratamiento y rehabilitación de la invidencia han reducido los problemas visuales desde 1995, fecha en la cual este tema fue incluido en la agenda de las reuniones de la Organización Mundial de la Salud. Sin embargo, una vez que existe ceguera, los servicios ofrecidos para las personas con ceguera se enfocan en el acceso a atención médica, acceso a la educación y cursos para el desarrollo de habilidades instrumentales. Sin minimizar la importancia de estos recursos, el acceso a apoyo emotional parece limitado, solamente ofrecido por pocas organizaciones en países específicos. El propósito de este proyecto es explorar la percepción de la ceguera y el apoyo emotional en los centros de rehabilitación a la ceguera en México. Si usted está de acuerdo en formar parte del estudio, se le solicitará participar en 1 o 2 entrevistas utilizando el método Psico-Social llamado Método Biográfico Narrativo Interpretativo (*Biographic-Narrative Interpretative Method)*

Ética

Este estudio ha recibido aprobación para realizarse por parte del Comité de Ética de la Facultad de Salud y Ciencias Sociales de la Universidad del Oeste de Inglaterra (*University of the West of England*). El proyecto está siendo supervisado por la Dra. Lita Crociani- Windland, quien puede ser contactada a través del correo lita.crociani-windland@uwe.ac.uk si se requiere mayor detalle respecto de los procedimientos éticos de este estudio.

En el reporte final, usted no será identificado, todos los participantes, y su información, será anónima.

Selección de participantes

Usted ha sido seleccionado para participar por ser usuario de los servicios de un centro de rehabilitación para la invidencia. Su experiencia es una valiosa contribución para este proyecto ya que permite explorar la percepción de la invidencia.

¿Qué tengo que hacer si decido participar?

Si usted decide ser parte del estudio, se le pedirá que participe en 1 o 2 entrevistas utilizando el Método Biográfico Narrativo Interpretativo (*Biographic-Narrative Interpretative Method),* en las que se le pedirá un recuento autobiográfico de sus experiencias relativas a la pérdida de la vista. Cada entrevista tendrá una duración de aproximadamente 60 minutos y se llevará a cabo en un tiempo y espacio acordado. Con su consentimiento, la actividad será audio-grabada y las grabaciones destruidas al término del proyecto.

¿Y si decido no participar?

Usted puede decidir no participar en el estudio, o abandonar la entrevista en cualquier momento. Si usted desea retirar sus datos de la investigación, puede hacerlo antes de Enero 2022. Usted no tiene ninguna obligación de dar razones por las cuales decide no participar en la investigación o retirar su información.

¿Hay posibles riesgos de participar?

Se le solicitará que asocie libremente sobre temas relacionados a la invidencia, es posible que hablar de estos temas puede causar ansiedad. La investigadora es una terapeuta con licencia capaz de proveer contención emocional y referencia terapéutica en caso de ser necesario. Si hay información en la cual la investigadora considere necesario romper la confidencialidad, esto será discutido con usted personalmente en un momento posterior a la actividad.

¿Hay posibles beneficios de participar?

Se espera que este estudio ayude a crear un entendimiento sobre la percepción que se tiene hacia la ceguera y apoyo emocional en los centros de rehabilitación a la ceguera con el fin de crear herramientas psico-sociales que puedan facilitar la adaptación a la invidencia de una persona con pérdida visual.

Uso de los datos

Los resultados de este estudio serán incluidos en la disertación final, con fecha en Octubre 2023. Con su autorización, estos datos serán incluidos en investigaciones posteriores. Diseminación adicional incluyendo presentaciones en congreso y publicaciones no mencionarán respuestas específicas de los participantes.

CONSENTIMIENTO INFORMADO

Título del Proyecto: La percepción de la ceguera y su impacto en la implementación de apoyo emocional para la pérdida visual en México: un Estudio Psico-Social.

The perception of blindness and its impact in the implementation of emotional support for sight loss in Mexico: a Psycho-Social Study

Nombre y datos de contacto de la investigadora: Leslie Marian Thompson García, M.Sc.
Teléfono: +52 (81) 20 01 77 18
Email: leslie2.thompson@live.uwe.ac.uk

……………………………………………………………………………………………

La confirmación del participante y detalles de contacto serán audio-grabadas.

- He leído y entiendo la información proporcionada por el documento anterior y he tenido la oportunidad de hacer preguntas.
- Entiendo que puedo contactar a la investigadora o la supervisora del proyecto para discutir cualquier aspecto de la actividad antes, durante o después de participar en ella.
- Entiendo que puedo retirarme del estudio en cualquier momento sin consecuencia alguna.
- Estoy de acuerdo con que si deseo retirar mi información del estudio debo hacerlo antes de Enero 2022
- Estoy de acuerdo con que la actividad será audio-grabada.
- Doy mi consentimiento para participar en las entrevistas
- Estoy de acuerdo en que se utilicen notas anónimas de esta actividad en la tesis escrita para la obtención del grado Doctoral en Estudios Psico-Sociales de la investigadora.
- Estoy de acuerdo con que los datos de este estudio se utilicen en proyectos de investigación posteriores.

Información de contacto

Nombre……………………………………………………………………………………..

Firma………………………………………………………………………………………….

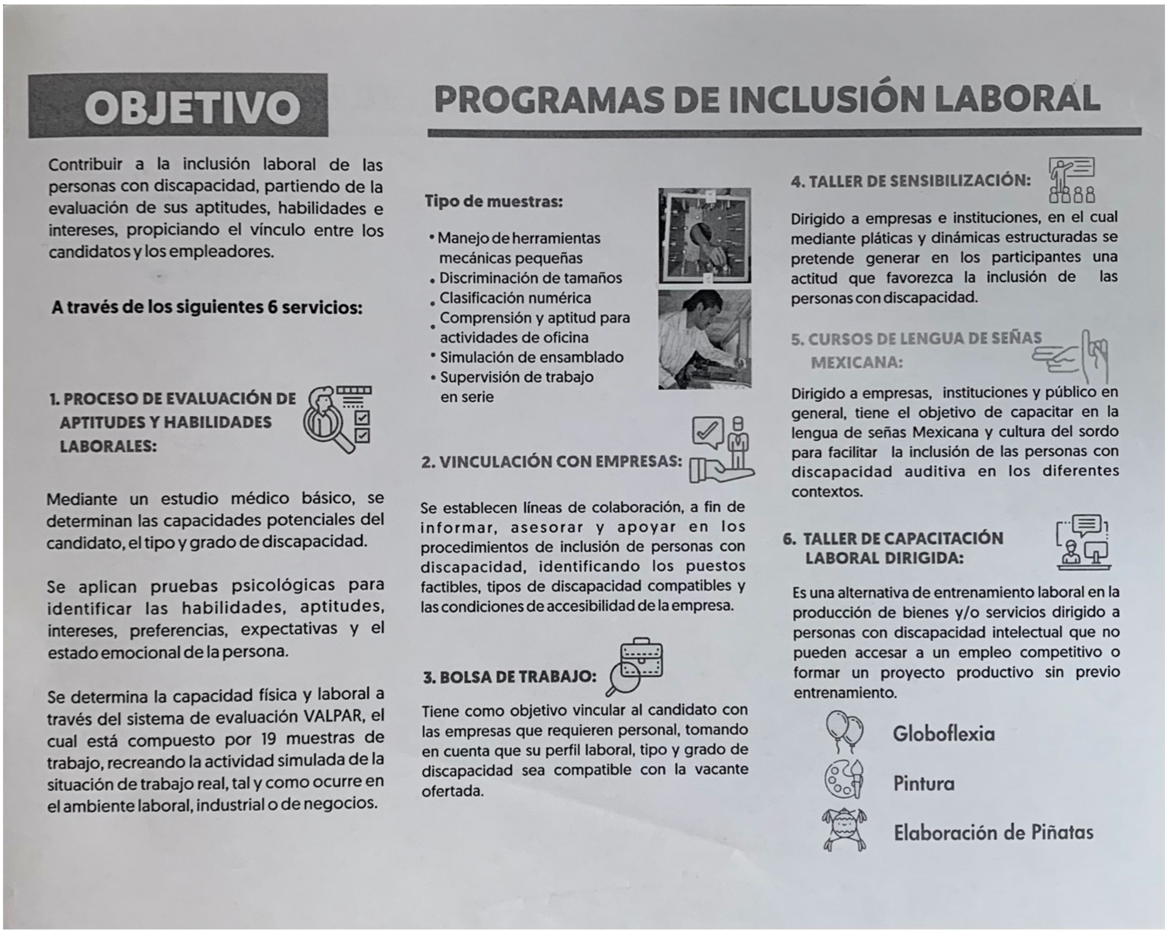
Fecha…………………………………………………………………………………………

Número telefónico…………………………………………………………………..

Correo………………………………………………………………………………………..

9.5 Public documents

Flyer with the information of the inclusion services provided by the public rehabilitation centre



OBJETIVO

Contribuir a la inclusión laboral de las personas con discapacidad, partiendo de la evaluación de sus aptitudes, habilidades e intereses, propiciando el vínculo entre los candidatos y los empleadores.

A través de los siguientes 6 servicios:

1. PROCESO DE EVALUACIÓN DE APTITUDES Y HABILIDADES LABORALES:

Mediante un estudio médico básico, se determinan las capacidades potenciales del candidato, el tipo y grado de discapacidad.

Se aplican pruebas psicológicas para identificar las habilidades, aptitudes, intereses, preferencias, expectativas y el estado emocional de la persona.

Se determina la capacidad física y laboral a través del sistema de evaluación VALPAR, el cual está compuesto por 19 muestras de trabajo, recreando la actividad simulada de la situación de trabajo real, tal y como ocurre en el ambiente laboral, industrial o de negocios.

PROGRAMAS DE INCLUSIÓN LABORAL

Tipo de muestras:

- Manejo de herramientas mecánicas pequeñas
- Discriminación de tamaños
- Clasificación numérica
- Comprensión y aptitud para actividades de oficina
- Simulación de ensamblado
- Supervisión de trabajo en serie

2. VINCULACIÓN CON EMPRESAS:

Se establecen líneas de colaboración, a fin de informar, asesorar y apoyar en los procedimientos de inclusión de personas con discapacidad, identificando los puestos factibles, tipos de discapacidad compatibles y las condiciones de accesibilidad de la empresa.

3. BOLSA DE TRABAJO:

Tiene como objetivo vincular al candidato con las empresas que requieren personal, tomando en cuenta que su perfil laboral, tipo y grado de discapacidad sea compatible con la vacante ofertada.

4. TALLER DE SENSIBILIZACIÓN:

Dirigido a empresas e instituciones, en el cual mediante pláticas y dinámicas estructuradas se pretende generar en los participantes una actitud que favorezca la inclusión de las personas con discapacidad.

5. CURSOS DE LENGUA DE SEÑAS MEXICANA:

Dirigido a empresas, instituciones y público en general, tiene el objetivo de capacitar en la lengua de señas Mexicana y cultura del sordo para facilitar la inclusión de las personas con discapacidad auditiva en los diferentes contextos.

6. TALLER DE CAPACITACIÓN LABORAL DIRIGIDA:

Es una alternativa de entrenamiento laboral en la producción de bienes y/o servicios dirigido a personas con discapacidad intelectual que no pueden accesar a un empleo competitivo o formar un proyecto productivo sin previo entrenamiento.

- Globoflexia
- Pintura
- Elaboración de Piñatas

9.6 Impact of this research

9.6.1 Maccia protocol in Spanish

MACCIA
Construyendo otra mirad

Protocolo
Maccia

Acompañamiento Terapéutico en la
Pérdida Visual

Desarrollado por
Mtra. Leslie Thompson

Consultora
Dra. Mhairi Thurston
Dra. Amanda Hawkins

Dirigido a

- Psicólogos clínicos que busquen especializarse en el acompañamiento terapéutico para personas con pérdida visual.

- Oftalmólogos, rehabilitadores visuales, trabajadores sociales, y todo personal que labore con personas con ceguera y discapacidad visual.

Modalidad

- Presencial (con opción a modalidad virtual por situación extraordinaria)
- Mínimo de participantes por grupo: 3

Frecuencia

- Personal no psicólogo: 9 horas (3 días de 3 horas)

- Psicólogos: 12 horas (4 días de 3 horas)

Blindness, by Yossi Kotler (2019)

Objetivos generales del programa del curso

Personal no- psicólogo: Al finalizar el curso el participante habrá adquirido conocimientos teóricos sobre el panorama actual de las personas con ceguera y discapacidad visual a nivel nacional e internacional, así como los referentes sociales y psicológicos que envuelven el proceso de duelo ante la pérdida visual y la adaptación a la ceguera. El participante adquirirá herramientas básicas de contención emocional y referencia a atención profesional que podrá utilizar en su trabajo diario con personas con pérdida y discapacidad visual.

Psicólogos: Al finalizar el curso el participante utilizará las herramientas aprendidas para asegurar el estándar de calidad en el Acompañamiento Terapéutico para las personas con pérdida visual. El alumno adquirirá el conocimiento teórico-práctico para implementar el Modelo Maccia en sus abordajes individuales, familiares y grupales, además de conocer e implementar las modificaciones infraestructurales, técnicas y clínicas para ofrecer un servicio óptimo al trabajar con esta población.

Temario

Módulo 1.- Marco de referencia sobre la ceguera y discapacidad visual

- 1.1 Definiciones de ceguera y discapacidad visual
- 1.2 Prevalencia y principales causas de pérdida visual
- 1.3 Respuesta de la Organización Mundial de la Salud
- 1.4 Panorama en México y Nuevo León
- 1.5 Referentes internacionales de incorporación de un protocolo de salud mental ante la pérdida visual
  - 1.5.1 Royal National Institute of the Blind (Reino Unido)
  - 1.5.2 Organización Nacional de Ciegos de España (España)

Modulo 2.- Referentes sociales sobre la ceguera y discapacidad visual

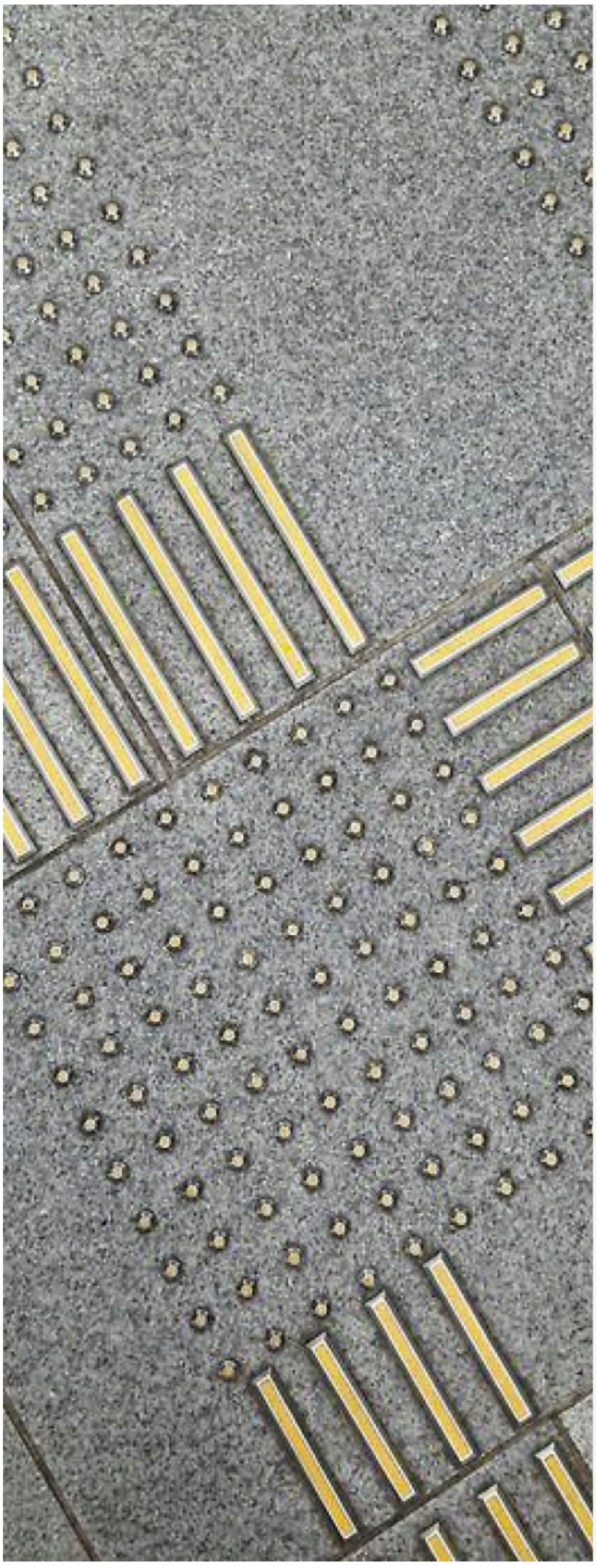
- 2.1 Referencias culturales e históricas sobre la ceguera
- 2.2 Capacitismo, discapacidad y pérdida visual
- 2.3 Modelos de discapacidad
- 2.4 Características de la sociedad mexicana
  - 2.4.1 Modelo de la caridad
  - 2.4.2 Roles de género tradicionales
  - 2.4.3 Sobreprotección familiar
  - 2.4.4 Limitaciones de inclusión educativas y laborales

Modulo 3.- Referentes psicológicos del proceso de duelo en la pérdida visual

- 3.1 El rol de la vista en la formación de la identidad y las consecuencias de su pérdida.
- 3.2 Ceguera congénita y ceguera adquirida
- 3.3 El proceso de duelo en la pérdida visual: Modelo Thurston
- 3.4 Herramientas de contención emocional y referencia a acompañamiento terapéutico para personal en general
- 3.5 Técnicas de autocuidado

Modulo 4.- Protocolo Maccia: Modelo de acompañamiento terapéutico para la pérdida visual. Únicamente para psicólogos

- 4.1 Definiciones clínicas
- 4.2 Objetivo
- 4.2 Herramientas de evaluación
- 4.3 Abordaje individual
- 4.4 Abordaje familiar
- 4.5 Abordaje grupal
- 4.6 Modificaciones infraestructurales, técnicas y clínicas



Perfil al finalizar el curso

Personal que trabaje con personas con pérdida y discapacidad visual.
No psicólogos

Conocimientos

- Tener un marco de referencia sobre la ceguera y discapacidad visual nacional e internacional
- Conocer los referentes sociales que envuelven la ceguera y discapacidad visual a nivel general y en México
- Reconocer las implicaciones emocionales de la pérdida visual
- Desarrollar herramientas de contención emocional y referencia a acompañamiento terapéutico para personas con ceguera y discapacidad visual, así como técnicas de autocuidado emocional

Habilidades genéricas

- Reflexión
- Introspección
- Escucha Activa
- Empatía
- Autocuidado

Perfil al finalizar el curso

Psicólogos

Conocimientos

- Tener un marco de referencia sobre la ceguera y discapacidad visual nacional e internacional
- Conocer los referentes sociales que envuelven la ceguera y discapacidad visual a nivel general y en México
- Reconocer las implicaciones emocionales de la pérdida visual
- Proporcionar acompañamiento terapéutico para personas con pérdida visual a nivel individual, familiar y grupal
- Conocer y realizar las modificaciones infraestructurales, técnicas y clínicas para el acompañamiento terapéutico para personas con pérdida visual

Habilidades genéricas

- Reflexión
- Introspección
- Escucha Activa
- Empatía
- Autocuidado
- Entrevista
- Intervención

Entregables (Psicólogos):

- Al finalizar el curso el alumno tendrá un examen final en el que demostrará la adquisición de conocimientos teóricos y clínicos para proveer acompañamiento terapéutico para personas con pérdida visual
- El alumno entregará un escrito final en el que reflexione sobre alguno de sus casos siguiendo el protocolo Maccia, mismo que presentará en la evaluación final.

Reconocimientos:

- Personal **no psicólogo**: Al finalizar el curso el alumno recibirá un certificado de participación que avala el conocimiento adquirido.
- **Psicólogos**: Al finalizar el curso el alumno recibirá un certificado que lo avala como acompañante terapéutico para personas con pérdida visual utilizando el protocolo Maccia.

Módulo 1

Marco de referencia sobre la ceguera y discapacidad visual

Al finalizar el módulo el estudiante conocerá sobre las definiciones de ceguera y discapacidad visual, la prevalencia y principales causas de la ceguera, la respuesta de la OMS ante la situación global de trastornos visuales, el panorama actual en México y Nuevo León de las personas con ceguera y discapacidad visual, y los referentes internacionales de incorporación de un protocolo de salud mental ante la pérdida visual.

Memories can't wait, Cane Dojcilovic

Temas y subtemas

- Definiciones de ceguera y discapacidad visual
- Prevalencia y principales causas de pérdida visual
- Respuesta de la Organización Mundial de la Salud
- Panorama en México y Nuevo León
- Referentes internacionales de incorporación de un protocolo de acompañamiento terapéutico ante la pérdida visual
  - Royal National Institute of the Blind (Reino Unido)
  - Organización Nacional de Ciegos de España (España)

Actividades en clase

Los participantes harán una reflexión grupal sobre sus experiencias, conocimiento y opiniones sobre el panorama actual en temas de ceguera y discapacidad visual

Ponderación

Participación en actividades: 40%
Reflexión y adquisición de conocimiento: 60%
Total: 100%

Módulo 2

Referentes sociales sobre la ceguera y discapacidad visual

Transference, Nikki Floyd

Al finalizar el módulo el estudiante conocerá sobre las referencias culturales e históricas sobre la ceguera, los conceptos sociales en términos de capacitismo y discapacidad que enmarcan la pérdida visual y los modelos de discapacidad. También reflexionará sobre las características de la sociedad mexicana que influyen en el proceso de adaptación a la pérdida visual.

Temas y subtemas

- Referencias culturales e históricas sobre la ceguera
- Capacitismo, discapacidad y pérdida visual
- Modelos de discapacidad
- Características de la sociedad mexicana
    - Modelo de la caridad
    - Roles de género tradicionales
    - Sobreprotección familiar
    - Limitaciones de inclusión educativas y laborales

Actividades en clase

- Los participantes harán una reflexión personal sobre lo que para ellos significa la ceguera y de dónde han construido este significado. Posteriormente se hará una reflexión grupal en la que se cuestionará este significado
- En equipos pequeños (2-3 personas) harán una reflexión sobre el capacitisimo, las características de los modelos de discapacidad y la sociedad mexicana (mencionadas o no) que han visto en sus casos de pérdida visual. Al finalizar con la actividad, cada equipo expondrá sus reflexiones

Ponderación	Participación en actividades: 40% Reflexión y adquisición de conocimiento: 60% Total: 100%

Módulo 3

Referentes psicológicos del proceso de duelo en la pérdida visual

Al finalizar el módulo el estudiante conocerá sobre el rol de la vista en el proceso de la formación de la identidad y las consecuencias emocionales de su pérdida, las diferencias psicológicas entre la ceguera congénita y adquirida, y el proceso de duelo en la pérdida visual (Modelo Thurston). Además, se desarrollarán herramientas de contención emocional y referencia a acompañamiento terapéutico para personal en general (no psicólogos).

Memories can't wait, Cane Dojcilovic

Temas y subtemas

- El rol de la vista en la formación de la identidad y las consecuencias de su pérdida.
- Ceguera congénita y ceguera adquirida
- Modelo de las cinco etapas de la Pérdida Visual: Mhairi Thurston
- Herramientas de contención emocional y referencia a acompañamiento terapéutico para personal en general
- Técnicas de autocuidado

Actividades en clase

- En equipos de 2-3 personas presentarán distintos casos de personas con pérdida visual en los cuales deberán identificar la etapa del proceso de duelo en que se encuentre y cómo darían trabajarían con ese caso. Posteriormente se presentarán al grupo sus reflexiones
- En una dinámica grupal se reflexionará sobre las dificultades del trabajo con personas con pérdida y discapacidad visual y las diferentes técnicas de autocuidado

Ponderación

Participación en actividades: 40%
Reflexión y adquisición de conocimiento: 60%
Total: 100%

Módulo 4

Modelo de acompañamiento terapéutico para la pérdida visual
(Únicamente para Psicólogos)


Joseph Lu

Al finalizar el módulo el estudiante conocerá las definiciones e intervenciones clínicas, y sabrá aplicar de manera adecuada el protocolo Maccia en sus abordajes individuales, familiares y grupales. Además, el alumno conocerá las modificaciones infraestructurales, técnicas y clínicas para una buena práctica al trabajar con pacientes con pérdida y discapacidad visual.

Temas y subtemas

- Definiciones clínicas
- Objetivo
- Herramientas de evaluación
- Abordaje individual
- Abordaje familiar
- Abordaje grupal
- Modificaciones infraestructurales, técnicas y clínicas

Actividades en clase

- Los alumnos realizarán actividades de role playing, simulando intervenciones individuales en situaciones reales. El grupo reflexionará sobre las intervenciones realizadas
- En equipos de 2-3 personas discutirán sobre distintos casos de intervenciones familiares al momento de trabajar con personas con pérdida visual. El grupo reflexionará sobre los retos que representan las intervenciones familiares y cómo abordarlas
- En equipos de 2-3 personas discutirán sobre los elementos a considerar en las intervenciones grupales con personas con pérdida visual. El grupo reflexionará sobre los retos que representan las intervenciones grupales y cómo abordarlas

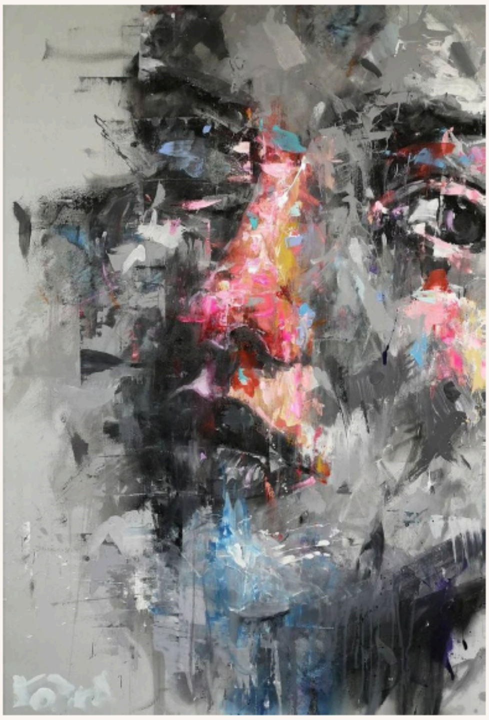
Ponderación

Participación en actividades: 40%
Reflexión y adquisición de conocimiento: 60%
Total: 100%

Módulo 5

Evaluación Final
(Únicamente para Psicólogos)

El objetivo del módulo es dar cierre al curso. Los alumnos tendrán una evaluación teórico-práctica en la que se demostrará la adquisición de conocimiento teórico y habilidades clínicas. En el apartado teórico, los alumnos harán una presentación de aproximadamente 30 minutos sobre el caso que hayan elegido y su abordaje utilizando el protocolo Maccia. Este caso deberá entregarse en extenso en escrito, incluyendo el abordaje clínico y reflexiones sobre el caso.



Dejan Bozinovski

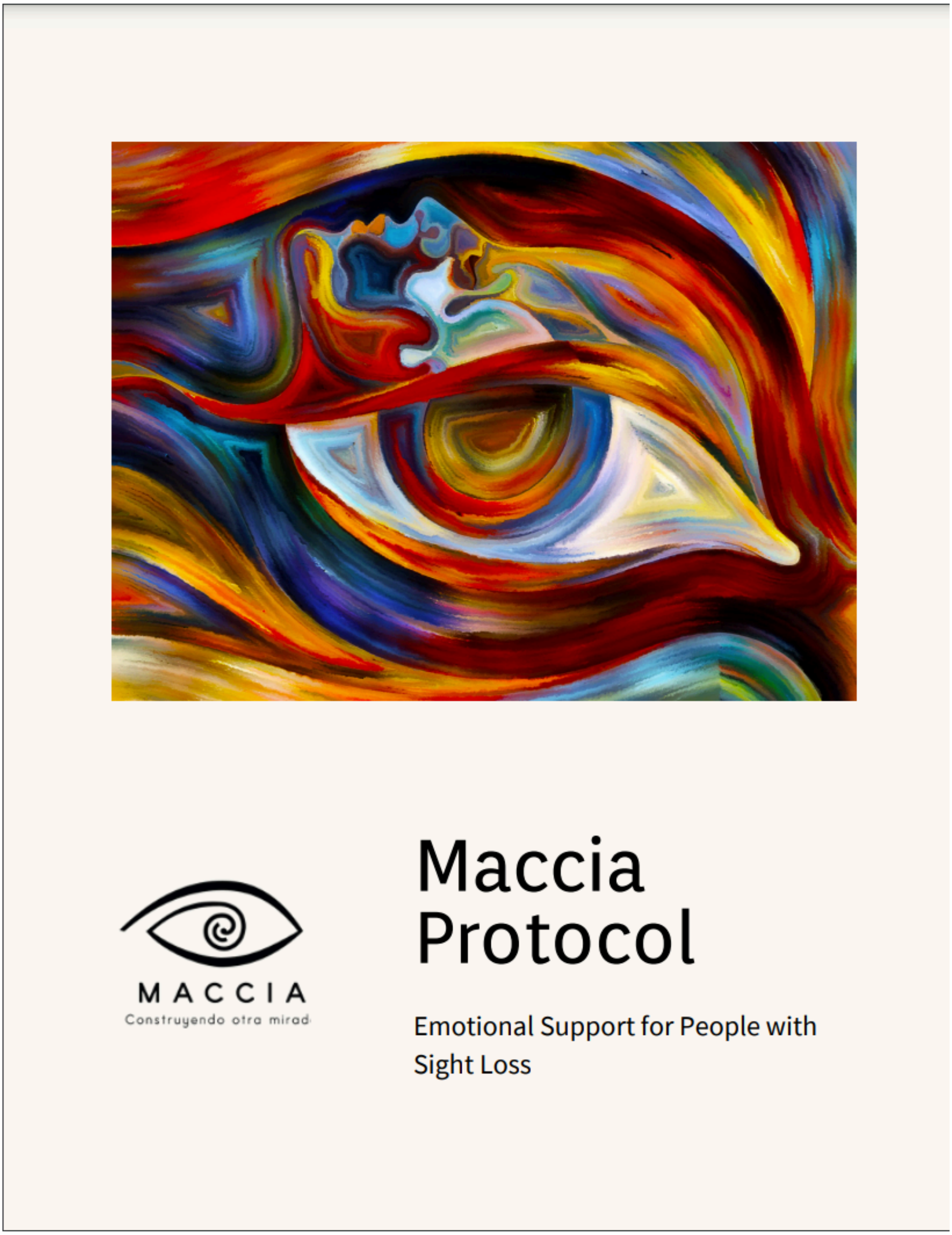
Ponderación Evaluación final

Examen teórico: 30%
Exposición final: 30%
Trabajo final 40%
Total: 100%

Módulo I: 15%
Módulo II: 15%
Módulo III: 15%
Módulo IV (taller): 20%
Evaluación final: 35%
Total: 100%

Composición de la calificación final

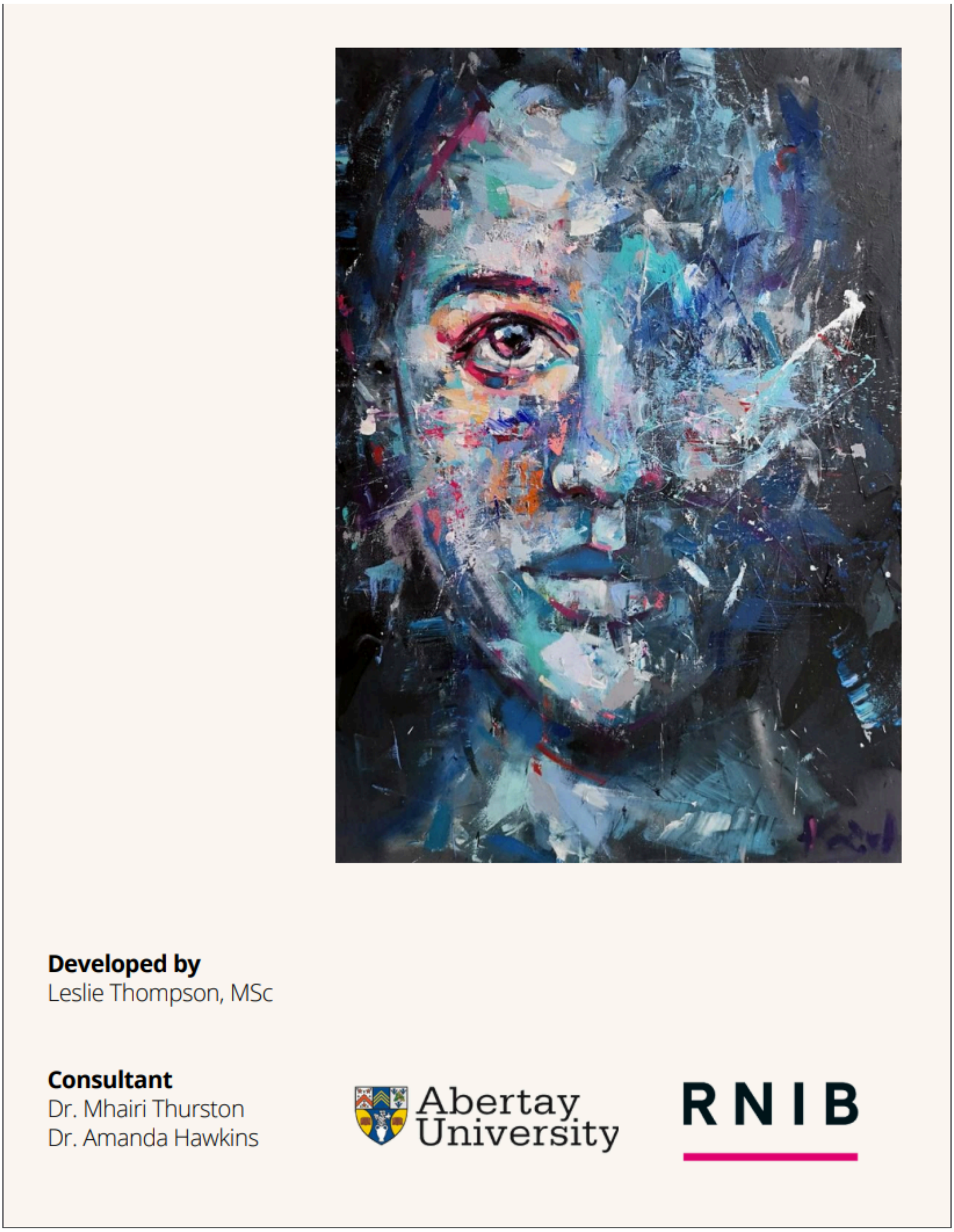
9.6.2 Maccia protocol in English



MACCIA
Construyendo otra mirad

Maccia Protocol

Emotional Support for People with Sight Loss



Developed by
Leslie Thompson, MSc

Consultant
Dr. Mhairi Thurston
Dr. Amanda Hawkins

Abertay University

RNIB

Leslie M. Nolan

Addressed to

- Clinical psychologists who seek to specialise in emotional support for people with sight loss.
- Ophthalmologists, visual rehabilitators, social workers, and all personnel working with people with blindness and visual loss.

Delivery Mode

- In-person/ online.
- Minimum number of participants per group: 3

Frequency

- Non-psychologist participants: 9 hours (3 days, 3 hours each day).
- Psychologists: 15 hours (3 days of 3 hours each + 1 day of 4-hour workshop + 1 day of 2-hour final exam).

Blindness, by Yossi Kotler (2019)

General objectives of the course

Non-psychologist participants: By the end of the course, participants will acquire theoretical knowledge about the current situation of individuals with blindness and visual impairments at national and international levels, alongside an understanding of the social and psychological factors that underlie the adjustment process of sight loss. Participants will acquire basic tools for emotional support and references to professional care that can be used by individuals with sight loss, blindness and visual impairments.

Psychologists: By the end of the course, participants will use the learned tools to ensure the standard of quality in providing emotional support for individuals with sight loss. Students will acquire theoretical-practical knowledge to implement the Maccia Model in their individual, family, and group approaches, in addition to learning and implementing infrastructure, technical, and clinical modifications to offer an optimal service when working with this population.

Profile on course completion

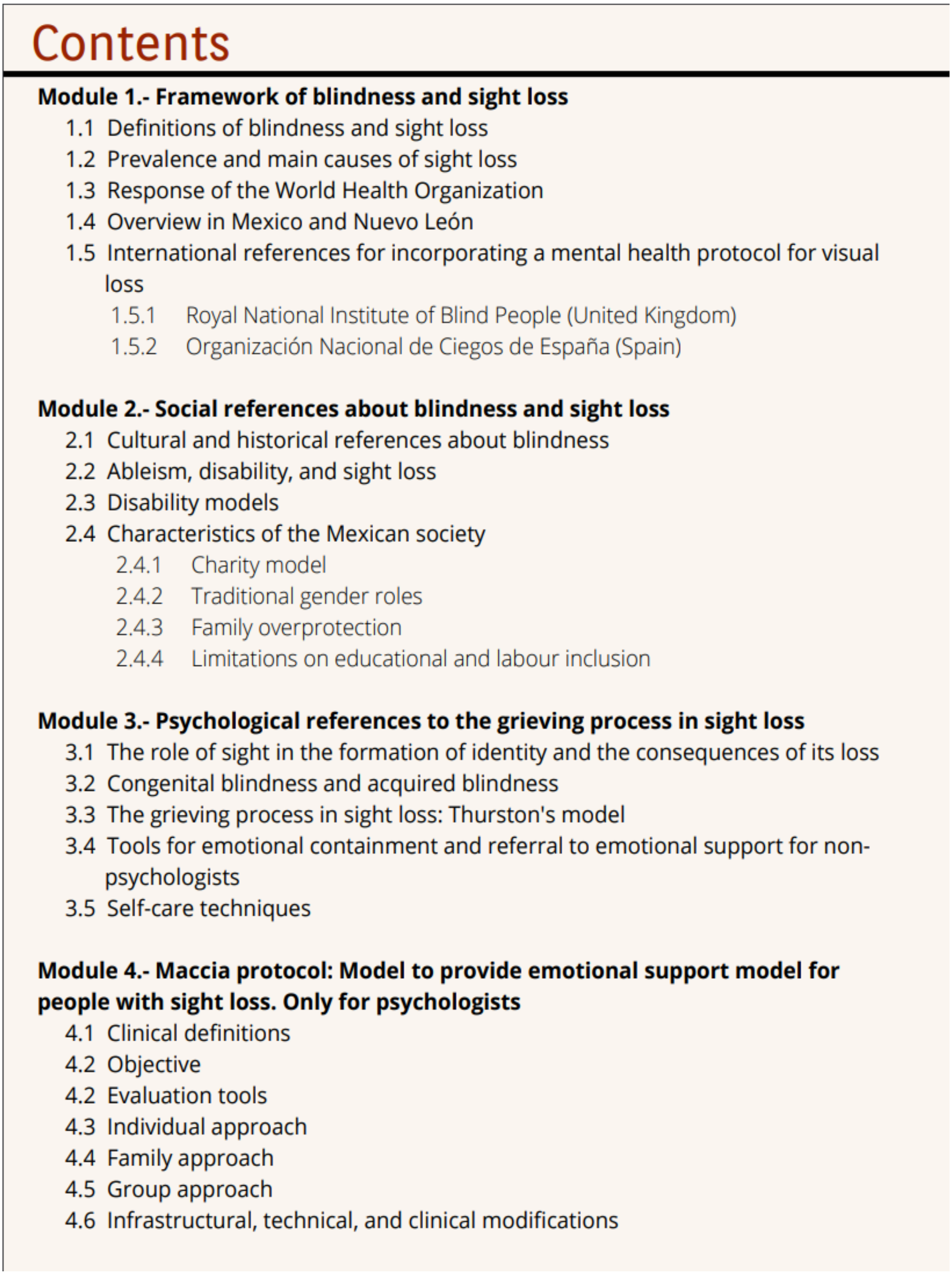
For individuals who work with people experiencing sight loss, regardless of their psychology background.

Knowledge and understandings

- Acquiring a national and international framework of reference on blindness and visual impairments
- Understanding the social factors that surround blindness and visual impairment at a general level and in Mexico.
- Recognising the emotional implications of sight loss.
- Developing emotional containment tools and referral to therapeutic support for people with sight loss and visual impairments, as well as techniques for emotional self-care.

Generic skills

- Reflection
- Introspection
- Active listening
- Empathy
- Self-care



Contents

Module 1.- Framework of blindness and sight loss

- 1.1 Definitions of blindness and sight loss
- 1.2 Prevalence and main causes of sight loss
- 1.3 Response of the World Health Organization
- 1.4 Overview in Mexico and Nuevo León
- 1.5 International references for incorporating a mental health protocol for visual loss
  - 1.5.1 Royal National Institute of Blind People (United Kingdom)
  - 1.5.2 Organización Nacional de Ciegos de España (Spain)

Module 2.- Social references about blindness and sight loss

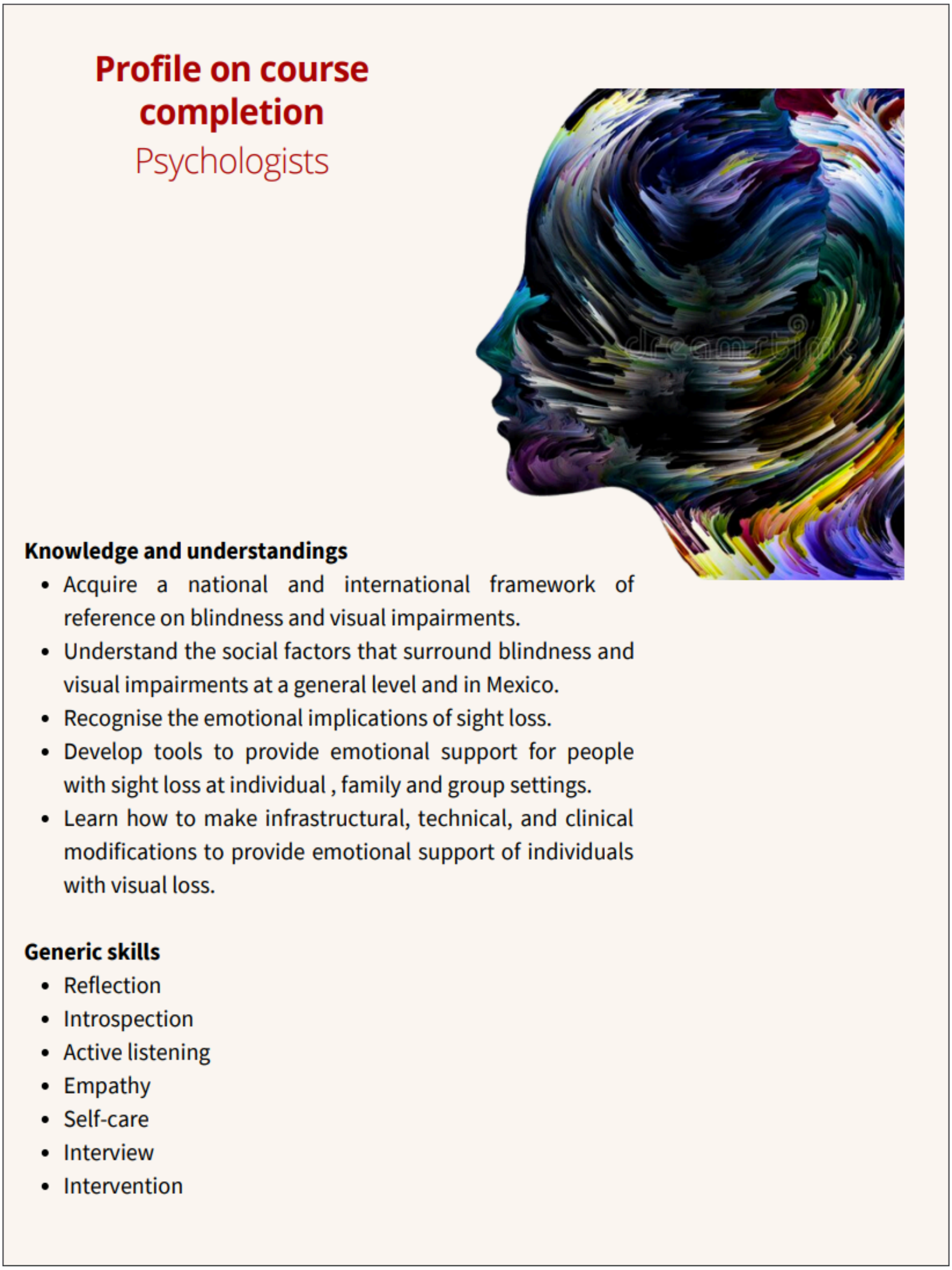
- 2.1 Cultural and historical references about blindness
- 2.2 Ableism, disability, and sight loss
- 2.3 Disability models
- 2.4 Characteristics of the Mexican society
  - 2.4.1 Charity model
  - 2.4.2 Traditional gender roles
  - 2.4.3 Family overprotection
  - 2.4.4 Limitations on educational and labour inclusion

Module 3.- Psychological references to the grieving process in sight loss

- 3.1 The role of sight in the formation of identity and the consequences of its loss
- 3.2 Congenital blindness and acquired blindness
- 3.3 The grieving process in sight loss: Thurston's model
- 3.4 Tools for emotional containment and referral to emotional support for non-psychologists
- 3.5 Self-care techniques

Module 4.- Maccia protocol: Model to provide emotional support model for people with sight loss. Only for psychologists

- 4.1 Clinical definitions
- 4.2 Objective
- 4.2 Evaluation tools
- 4.3 Individual approach
- 4.4 Family approach
- 4.5 Group approach
- 4.6 Infrastructural, technical, and clinical modifications



Profile on course completion

Psychologists

Knowledge and understandings

- Acquire a national and international framework of reference on blindness and visual impairments.
- Understand the social factors that surround blindness and visual impairments at a general level and in Mexico.
- Recognise the emotional implications of sight loss.
- Develop tools to provide emotional support for people with sight loss at individual , family and group settings.
- Learn how to make infrastructural, technical, and clinical modifications to provide emotional support of individuals with visual loss.

Generic skills

- Reflection
- Introspection
- Active listening
- Empathy
- Self-care
- Interview
- Intervention

Evaluation (Psychologists):

- A final exam will be administered at the end of the course where students will demonstrate acquisition of theoretical and clinical knowledge to provide emotional support for individuals with sight loss.
- A final written report must be completed where the student reflects upon the application of the Maccia project on a specific scenario. This will also be presented as part of the final evaluation.

Certificates:

- **Non-psychologists**: At the end of the course, the student will receive a certificate of participation that validates the acquired knowledge.
- **Psychologists**: At the end of the course, the student will receive a certificate that qualifies them to provide emotional support for individuals with sight loss.

Module 1
Framework of blindness and sight loss

At the end of the module, students will learn about the definitions of blindness and visual impairment, the prevalence and main causes of blindness, the response of the WHO to the global situation of visual conditions, the current situation in Mexico and Nuevo León of people with blindness and visual impairments, and international references for incorporating a mental health protocol for visual loss.


Memories can't wait, Cane Dojcilovic

Topics and subtopics

- Definitions of blindness and sight loss
- Prevalence and main causes of sight loss
- Response of the World Health Organisation
- Overview in Mexico and Nuevo León
- International references for incorporating a mental health protocol for sight loss
  - Royal National Institute of the Blind People(United Kingdom)
  - Organización Nacional de Ciegos de España (Spain)

Class assignments

Participants will engage in a group reflection on their experiences, knowledge, and opinions about the current situation regarding blindness and visual impairments.

Grading criteria

Participation in activities: 40%
Reflection and knowledge acquisition: 60%
Total: 100%

Module 2

Social references about blindness and sight loss

Transference, Nikki Floyd

Concluding this module, participants will gain insight into the cultural and historical references related to blindness, social concepts concerning ableism and disability that contextualise sight loss, and models of disability. Additionally, students will engage in reflection on the unique societal characteristics of Mexico that impact the adjustment process for people with sight loss.

Topics and subtopics

- Social references about blindness and sight loss
- Ableism, disability, and sight loss
- Disability models
- Characteristics of the Mexican society
  - Charity model
  - Traditional gender roles
  - Family overprotection
  - Limitations on educational and labour inclusion

Class assignments

- Participants will engage in a personal reflection on their individual perspectives and understanding of blindness, as well as explore the sources from which these ideas were formed. Following this, a group reflection will take place to critically examine the meaning of blindness.
- In small teams consisting of 2-3 individuals, participants will engage in a reflective exercise on the societal implications of ableism, the characteristics of disability models, and the characteristics of the Mexican society as related to visual loss. Upon completion of the exercise, the teams will present their reflections to the larger group.

Grading criteria

Participation in activities: 40%
Reflection and knowledge acquisition: 60%
Total: 100%

Module 3

Psychological references to the grieving process in visual loss

Upon completion of this module, students will learn about the role of sight in the process of identity formation, the emotional consequences of sight loss, psychological differences between congenital and acquired blindness, and the grieving process in sight loss (Thurston's Five Stages of Sight Loss). Additionally, tools for emotional containment and referral to emotional support for non-psychology students will be developed.

Memories can't wait, Cane Dojcilovic

Topics and subtopics

- The role of sight in the formation of identity and the consequences of its loss
- Congenital and acquired blindness
- Model of the Five Stages of Sight Loss: Mhairi Thurston
- Tools for emotional containment and referral to emotional support
- Self-care techniques

Class assignments

- In teams of 2-3 people, participants will analyse and present various cases of individuals with visual loss, identify the stage of grief, and develop potential interventions for each.
- A group reflection on the challenges of working with people with sight loss and visual impairements will be held, and relevant techniques for self-care will be discussed.

Grading criteria

Participation in activities: 40%
Reflection and knowledge acquisition: 60%
Total: 100%

Module 4

Emotional support protocol for people with sight loss
(Only for Psychologists)


Joseph Lu

Upon completion of this module, students will be familiar with key definitions and clinical approaches to work with people with sight loss at an individual, family, and group setting. Additionally, students will become familiar with the infrastructural, technical, and clinical modifications required for proper practice when working with patients with sight loss and visual impairments.

Topics and subtopics

- Clinical definitions
- Objective
- Evaluation tools
- Individual approach
- Family approach
- Group approach
- Infrastructural, technical, and clinical modifications

Class assignments

- Students will engage in role-playing activities simulating multiple individual interventions and reflect on the scenarios performed.
- In teams of 2-3, students will discuss different cases of family interventions when working with individuals with visual loss. Groups will discuss the challenges posed by family interventions and ways to approach them.
- In teams of 2-3, participants will discuss the various elements to consider for group interventions with individuals with visual loss. Group will reflect on the challenges posed by group interventions and discuss ways to approach them.

Grading criteria

Participation in activities: 40%
Reflection and knowledge acquisition: 60%
Total: 100%

Module 5

Final Evaluation
(Only for Psychologists)

The objective of this module is to provide closure to the course. Students will have a theoretical-practical evaluation in which the acquisition of theoretical knowledge and clinical skills will be demonstrated.

For the theoretical section, students will create a 30-minute presentation on a case of their choice and apply the emotional support protocol. The case must be submitted as a written report that includes the clinical approach and reflections on the case.


Dejan Bozinovski

Final evaluation grading criteria

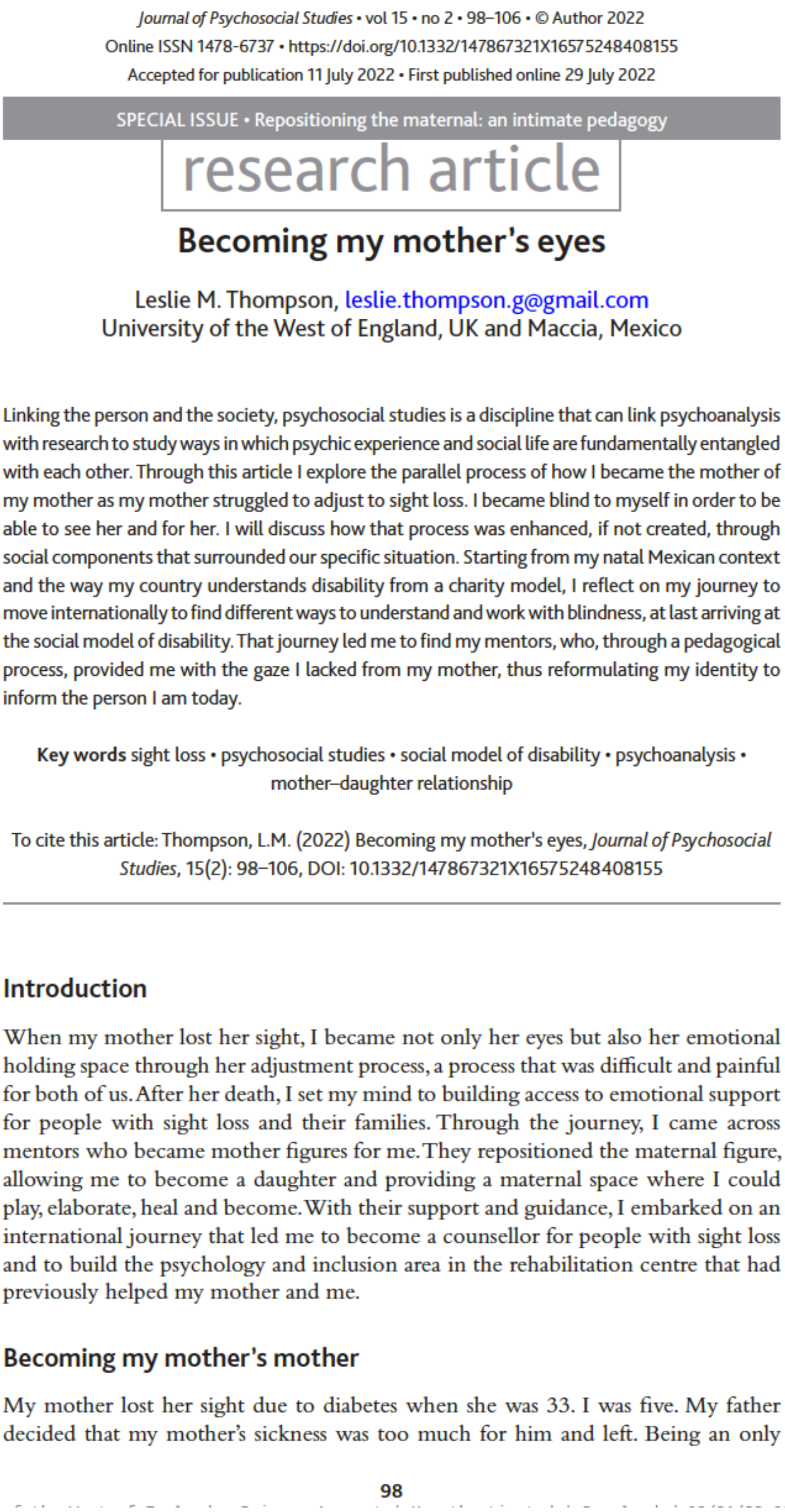
Theoretical exam: 30%
Final presentation: 30%
Final written report: 40%
Total: 100%

Final grade grading criteria

Module I: 15%
Module II: 15%
Module III: 15%
Module IV (taller): 20%
Final evaluation: 35%
Total: 100%

9.7 Publications

9.7.1 Thompson, L.M. (2022). Becoming my mother's eyes. *Journal of Psychosocial Studies,* 15(2): 98-106, DOI: 10.1332/147867321X16575248408155



Journal of Psychosocial Studies • vol 15 • no 2 • 98–106 • © Author 2022
Online ISSN 1478-6737 • https://doi.org/10.1332/147867321X16575248408155
Accepted for publication 11 July 2022 • First published online 29 July 2022

SPECIAL ISSUE • Repositioning the maternal: an intimate pedagogy

research article

Becoming my mother's eyes

Leslie M. Thompson, leslie.thompson.g@gmail.com
University of the West of England, UK and Maccia, Mexico

Linking the person and the society, psychosocial studies is a discipline that can link psychoanalysis with research to study ways in which psychic experience and social life are fundamentally entangled with each other. Through this article I explore the parallel process of how I became the mother of my mother as my mother struggled to adjust to sight loss. I became blind to myself in order to be able to see her and for her. I will discuss how that process was enhanced, if not created, through social components that surrounded our specific situation. Starting from my natal Mexican context and the way my country understands disability from a charity model, I reflect on my journey to move internationally to find different ways to understand and work with blindness, at last arriving at the social model of disability. That journey led me to find my mentors, who, through a pedagogical process, provided me with the gaze I lacked from my mother, thus reformulating my identity to inform the person I am today.

Key words sight loss • psychosocial studies • social model of disability • psychoanalysis • mother–daughter relationship

To cite this article: Thompson, L.M. (2022) Becoming my mother's eyes, *Journal of Psychosocial Studies*, 15(2): 98–106, DOI: 10.1332/147867321X16575248408155

Introduction

When my mother lost her sight, I became not only her eyes but also her emotional holding space through her adjustment process, a process that was difficult and painful for both of us. After her death, I set my mind to building access to emotional support for people with sight loss and their families. Through the journey, I came across mentors who became mother figures for me. They repositioned the maternal figure, allowing me to become a daughter and providing a maternal space where I could play, elaborate, heal and become. With their support and guidance, I embarked on an international journey that led me to become a counsellor for people with sight loss and to build the psychology and inclusion area in the rehabilitation centre that had previously helped my mother and me.

Becoming my mother's mother

My mother lost her sight due to diabetes when she was 33. I was five. My father decided that my mother's sickness was too much for him and left. Being an only child, the responsibility for my mother's medical care fell immediately onto me. On a regular day, I would wake up, bathe and dress my mother, feed her, test her blood pressure and glucose level to determine her medication, inject her with insulin and perform peritoneal dialysis on her (she also had kidney failure). Then I would get ready for school, walk to the house of a neighbour (who was the director of the school I attended), ride with her to school, attend my classes and come back with her (at a late hour because she was the director). Back at home, I would feed and dialyse my mother, do my homework, go to sleep and wake up at least three times a night because she wasn't feeling well and needed an insulin shot, pain medication or to throw up, or all of the above.

But why was a five-year-old doing this?

Perhaps this is partly explained by the social aspects surrounding disability in Mexico. In this country, the care of people with disabilities is characterised by inequalities. Three disability models can be located. First, the charity model identifies disabilities with imperfections, impurities, God's rage and the expiation of sins. This model has, on the one hand, the Christian discourse of compassion and, on the other, exclusion and punishment as people with disabilities are perceived as useless, dangerous and unnecessary. Segregation and abandonment are part of the charity model. Second, the medical/rehabilitation model discards the religious cause of disability in favour of a scientific aetiology and medical treatment. Disability is considered a deficiency, alteration or failure and a person with a disability can be usefully given the tools to rehabilitate and integrate. Third, the social model proposes that disability results from a society designed to meet only the needs of 'normal' people. Even though they are roughly located through time, these models are still present today (Sandoval et al, 2016).

Neither my mother nor I had a job, so we lived on any help my family or my mother's friends would give us. My mother's siblings helped us by being charitable and this seemed to entitle them to be critical of her, portraying her as personally responsible for her plight and dependency.

Medical public services in the city are operated by zone. Hence, the uncle closest to the hospital dedicated to nephrology registered us in the health system like we were living with him, so my mother could have the best care. Another aunt registered that we were living in her house for governmental purposes. They told me they were doing this to protect us because if anyone knew that we were living alone, my mother would be taken to prison and I would be sent to an orphanage. They made it clear to us that we were nothing and had nothing, and even though they had no responsibility to do so, they were helping us. I was grateful to them for feeding and protecting us. It took me 20 years to realise the negligence that they allowed to happen.

In that segregation, our adjustment process began. In order to survive, we got entangled in a relationship in which my mother needed me to stay alive, and I needed her alive, which became the sole purpose of my own life. I needed to keep her alive until I could find a way to heal her.

We adjusted our relationship to blindness. We learned Braille together and started training our hearing and tactile senses. I knew she was suffering emotionally from losing her sight, so I was trying to provide my support and company in her adjustment process to blindness. I tried to make life as usual as I was able to. I would describe everything to her, the people, the places, the floors and ceilings, all shapes and colours. I once took her to the movie theatre; we sat in the front row (away from the rest of the people there), and I read the subtitles and described the actors and actresses, their physical appearance, the clothes they were wearing and what they were doing in the movie.

I tried to hide anything that could produce emotional distress in her. I stretched money as much as I could so she wouldn't worry. I would rationalise meals, and when I anticipated it wouldn't be enough for us to eat, I would give her the food and make noises with the silverware against the plate to sound as though I was eating as well. I would constantly renounce eating so that she had something to eat the next day.

She never knew I did this. She was, as a regular mother would be, worried about my education and my grades. She would help me study by using a tape recorder on which I would tape what I needed to learn in school, and she would listen to the tape and quiz me. I believe she wanted to sustain the illusion that studying was my only responsibility as 'a normal child'. That couldn't be further away from my reality. My primary responsibility was to keep her alive. Nevertheless, I would sustain that illusion for her because I believed it made her feel like a mother, like the mother she would have wanted to be, perhaps, the mother she could have been.

My mother was sick and in pain, so my pain didn't have any place to exist. If I had any physical pain, I wouldn't tell her but would find the medication I needed. When I was sad or feeling the hopelessness of our situation, I would try to calm myself down and quietly cry, sometimes in front of her, without her realising. I've learnt how to cry without making any noise. I became not only her eyes but also her emotional holder. I became my mother's mother.

On our last journey to the hospital, one week before she died, we were in the ambulance, and the paramedic told me we needed to turn the siren on because my mother was dying and she needed to get to the hospital as fast as possible. I knew how frightened my mother was, so I asked the paramedic for a minute and went to my mother's side. "Mom," I said, "we're in an ambulance; how cool is that?" "Very cool," she said. She was in much pain. "I have an idea; why don't I ask the paramedic if we can turn on the siren so we can have the full experience?" Her face lightened, and she projected the emotion of a child on a rollercoaster. "Yeeeeees," she said. I signalled to the paramedic. They turned the siren on. The ambulance started speeding up. I was terrified.

Identity and sight: the relevance of emotional support through the adjustment process of sight loss

Identity is embodied for a person with a disability. Someone cannot be separated from their own body (Loja et al, 2012). For those born seeing and with a sighted mother, sight plays a crucial role in developing identity. The infant's first encounter in the formation of the self is registered through the eyes of the mother, being this the channel of projections and introjections (Winnicott, 1971).

Someone with acquired blindness is not only losing the possibility to perform in a world made for sighted people, but also the possibility of seeing themselves in the eyes of those around them. They lose their identity built upon visual stimuli. To be able to grieve, a renouncement must be made of a sighted person's identity to reconstruct a new identity as a person with blindness based on the remaining senses (Oyarzabal, 2007). For this to happen, a space must be created that provides enough holding for a person to explore the personal meaning of sight loss, to deconstruct and reconstruct their sense of identity – a transitional space; a therapeutic space.

My mother never renounced the possibility of sight. She had hope. She forgot colours and shapes as time passed and could only dream emotions, sensations, sounds and smells. She was devastated. The leading cause of disability is not necessarily the physical impairment, but depression. In creating a self-identity in a body with an impairment, a positive construction is constantly disabled by the ableist eye of society (Loja et al, 2012).

My mother and I lived in a city with two rehabilitation centres for people with blindness. One of those centres provided the material for us to learn Braille. Nonetheless, psychological attention was not a service provided by the centre. Neither my mother nor my family (nor I) sought emotional support for her. In Mexico, there's a stigma towards psychology. Psychotherapy is seen for 'weak' or 'crazy' people. Although it is slowly shifting towards a more accepting perspective, this stigma still exists today.

My mother died nine years after she lost her sight. She never adjusted, either practically or emotionally, to sight loss. She couldn't renounce the possibility of seeing. She kept hoping for a miracle that would allow her to see again, even when doctors told her she wouldn't. Hoping to see again and waking up every day in the same reality of not being able to see broke her. She was depressed and angry almost all the time. As much as I tried, there was a moment in which I couldn't hold her any longer. I was broken too. I was desperately trying to grow up so I could find a way to heal her. Once, as a 12-year-old, I begged a surgeon to take my kidney and give it to my mother. I needed to stop her (our) emotional pain. He replied that I was too young.

I needed her to wait until I was old enough to donate organs, study and find answers. To heal her. But she died when I was 14 years old. Her dying felt like my biggest failure. I had failed to keep my mother alive for enough time to heal her. Of course, in my child's mind, I was sure I would find a way to heal her even when all the doctors couldn't. This thought was, of course, a hopeful illusion.

Trying to heal in others what I couldn't heal in my mother: the start of my educational and professional trajectory

After her death, I made my life's purpose to make sure no one else would have to go through what my mother had to do and for no child to go through what I had to do. I needed to transform my failure, my pain, into something useful. I set a goal to try to heal in others what I couldn't heal in my mother.

I started my Bachelor's degree in psychology. My first idea for my final thesis project was to research the stages of the grieving process of sight loss. Reviewing the literature, I found that several models that explained the grieving process of sight loss already existed (Allen, 1989; Tuttle and Tuttle, 1996; Hayeems et al, 2005; Thurston, 2010). I was particularly interested in the model Mhairi Thurston (2010) developed because it was the only one that addressed the need to renounce an identity as a sighted person to reconstruct an identity as a person with blindness. Using that model as a reference, I changed my research project to explore the factors that aided or hindered the adjustment process of adults with acquired blindness using the life-history method.

The results of the study were consistent with the literature. Factors such as optimism, determination, a desire to adjust to sight loss, productivity, perseverance, independence and the presence of a support network were considered helpful in the adjustment process to sight loss. In contrast, a lack of purpose, difficulty in accepting sight loss, negative self-evaluation, dependence and feelings of vulnerability were found to hinder the process (Thompson et al, 2013).

What caught my attention was that when the colleagues I was doing this research with and myself arrived at the rehabilitation centre, they told us that the participants were already adapted to blindness and that interviewing them about their grieving process was a waste of time. We interviewed them anyway.

The participants talked about their difficulty in the adjustment process, and feelings of sadness, fear and anxiety. One of them mentioned having a loaded gun under his bed 'for the day when he can no longer endure the pain of not being able to see' (Thompson et al, 2013: 80). This complete opposition of ideas between the staff perception and the experience of the users of the rehabilitation centre was shocking. I couldn't understand why the centre ignored the service users' emotional experiences.

When we finished the research, we invited the staff from the centre to a presentation of the findings. We suggested that psychotherapy be added to the rehabilitation programme to address the emotional impact of sight loss. Afterwards, I made an appointment with the coordinator of the educational area to address this issue directly. She told me that she needed further justification to ask the council to hire a psychologist to include emotional support in the rehabilitation plan. I knew from my experience with my mother that the adjustment process of sight loss requires not only a physical adjustment but also emotional support. Nonetheless, I didn't have the tools at the time to explain why a psychotherapeutic process was crucial.

I knew by then that I wanted to be a clinical psychologist, but I didn't know which kind of clinical psychologist. So I took some time to read a bit more. I started working at the University of Monterrey in Mexico (my *alma mater*) as the administrator of a psychological clinic. Influenced by my boss, a brilliant psychoanalyst from whom I felt respect and admiration, and believing this was the right track to understanding the implications of the emotional impact of sight loss, I started a Master's degree in psychoanalysis.

Repeating the pattern and repositioning the maternal

In retrospect, perhaps studying at the same university I was working at was not the best decision. I was involved in the development and administration of the programme as part of my job. My boss was the programme director, and he and my colleagues at work were my professors and supervisors. I was stuck between wanting to do things right for my work and allowing myself to fail and learn in my academic and clinical process. I soon realised that I was doing whatever my boss told me to do, even if it didn't feel right for me.

We aimed to create the programme with international links, so I invited Dr Marilyn Charles, who I met at a conference of the American Psychological Association, to become a visiting professor. From then, she started travelling to Mexico and teaching seminars throughout the programme. I was in charge of every administrative aspect, the flights, her agenda, organising the classes and ensuring she got paid.

I had a double role with Marilyn. On the one hand, I needed to present myself as the person in charge of keeping her safe, a person whom she could trust with her life. On the other hand, she was my professor, the person I was learning from and with whom I needed to feel safe to fail and show her my mistakes to learn. She was a vivid representation of my mother.

Consciously or unconsciously, Marilyn took my mother's role, but she did it differently. She recognised and respected my position at the university and trusted me blindly to keep her safe in her travels and organise everything for her when she was in Mexico. However, she recognised that I was growing and learning, and I needed her guidance to become the clinician I wanted to be. She provided me a safe, maternal space to explore safely and learn. We both kept each other safe.

She became not only my mentor but also one of my dearest friends. With her guidance, I learnt to listen to myself and become an analyst with my own way of working. To learn from my experience, I asked her if she would be my thesis director. She accepted. In this research, I theorised about sight loss as a loss and reconstruction of identity using Freud's theorisation of grieving and mourning (Freud, 1966 [1914]) and Thurston's (2010) grieving model for sight loss. Marilyn was holding me as I explored and theorised about the most painful experience of my life.

Blindness is commonly recognised as losing an organ's function. Nonetheless, it has profound psychological implications. It represents the ability to perform in the world made by and for sighted people and the possibility to recognise and be recognised by others visually. To rebuild oneself using the remaining senses, one must accept blindness and renounce the possibility of seeing to reconstruct a new identity as a person with blindness (Lampl and Olivier, 1985). A psychological process is then crucial as a holding space to deconstruct and reconstruct this new identity.

After acquiring a Master's degree in clinical psychology, I returned to the rehabilitation centre where I had done my thesis for the Bachelor's degree, to deliver my Master's thesis as the answer to why emotional support was needed in the adjustment process of sight loss (Thompson, 2017). Additionally, I offered to provide psychotherapeutic services without cost to Master's students who were training for their clinical degree and supervised by professors. The centre's administration responded that people with sight loss didn't need a psychotherapeutic process to adjust to blindness. I felt devastated.

Knowing that psychotherapy could be a crucial factor that aided in the adjustment process to sight loss, I immediately set my mind to answer the following questions: Why was this the perception of the rehabilitation centre? What was the centre *seeing*, and why couldn't they *see* the emotional experience of the people going through a grieving process for sight loss?

Marilyn had opened the world to me. She invited me to participate in the Association for the Psychoanalysis of Culture and Society conference, presenting my thesis. At that conference, I started listening about psychosocial studies and the intersection it provided to research a sociological problem from a psychoanalytical standpoint using a qualitative methodology. I thought it was perfect for what I wanted to address. Marilyn suggested I apply to the PhD programme in psychosocial studies at the University of the West of England in the United Kingdom (UK) – Lita's Crociani-Windland's programme. I had never talked with Lita before.

At the following year's conference, Lita approached me and said that Marilyn had talked to her, and she wanted to know about my research. I nervously explained my history to her, and she encouraged me to apply to the programme. I did, and she became my thesis director of studies.

Lita quickly became a mother figure for me. One year into the programme, at my first progression examination, I was very nervous. She was allowed to be in the room, but we couldn't make eye contact. She handed me a little box for me to hold in my hand and said: "This would remind you I'm there with you. Fidget with it when you feel nervous." She handed me a transitional object, and I knew right there that she loved me as a mother.

Lita would welcome me to stay in her house through the PhD programme. She and her partner have the tradition of having tea after dinner in the living room. Once we were casually talking about the origins of the British crown, and I thought: "This is what having a family must feel like." I cherish that memory deeply in my heart.

My doctoral thesis project explores the perception of blindness and the needs and obstacles in relation to implementing psychodynamic psychotherapy in the rehabilitation centres for blindness in Mexico. This is the first study conducted in Mexico that explores blindness from a psychosocial perspective, using a psychoanalytic lens and the theoretical bases of the social model of disability. It is the first step towards generating awareness and aiming for the future inclusion of a psychotherapeutic process in rehabilitation centres for blindness.

Through the journey, I approached the Royal National Institute of Blind People in the UK. I told them I wanted to learn from them and bring that knowledge to Mexico. They opened their doors for me and let me learn anything I needed from them. They directed me to the psychology area and explained there was a seminar to become a counsellor for people with sight loss. I applied immediately and took the course, becoming the first counsellor for sight loss in Mexico. This course was given by Mhairi Thurston, whose research I have been following for ten years. After taking the course, I asked for an appointment with her. I explained that I was following in her footsteps and trying to build in Mexico what she had in the UK. She became a consultant in my PhD project and is still guiding my journey into implementing emotional support for people with sight loss in the rehabilitation centres for blindness in Mexico.

Arriving to the end of the journey: becoming an activist and setting up the psychology area for people with sight loss

The goal I had set when my mother died has transformed. I wanted to make the emotional challenges of adjusting to sight loss visible by implementing psychotherapy as part of the adjustment process. I used to think psychotherapy was the answer to healing that pain.

Perhaps having a space to talk about what she felt could have helped my mother work through her grieving process and adjust to sight loss. Maybe it wouldn't. Perhaps she would have decided not to talk about it. All I know is that it wasn't an option for her. For us.

I understand now that emotional reactions are not the same for everyone, and not everyone needs psychotherapy to adjust to sight loss. Still, some people might either need or benefit from having a space to work through the emotional process of losing their sight, and I believe it is a service that should be offered to whoever wants to take it. Perhaps it is my desire to believe my mother would have been one of them and that her life and mine could have been emotionally less painful.

Through time, things have changed in the rehabilitation centre that had previously helped my mother and me. As I was conducting the interviews for the PhD project, I learnt that a volunteer psychologist provided psychological attention. "She does what she can, but we're in urgent need to structure a psychology area," mentioned the director of the educational area. She had been addressing this need with the council, but she faced resistance to investing in this resource, along with the same reply I got five years ago: "Psychotherapy isn't needed for someone to adjust to sight loss."

Surprisingly, after my interview with one of the council members, the council decided to let go of the volunteer and hire a psychologist. The director of the educational area mentioned that at a council meeting, the council member I had interviewed addressed the need to hire a psychologist. "I don't know what you told him, but this finally moved. They agreed to hire someone part-time for the moment, and then we'll see depending on the demand." She then asked for my help as a consultant to build the psychology area.

Given the previous resistance both the director of services and I faced incorporating psychological attention, the resolution of hiring a psychologist (even if part-time) and the invitation to contribute to her training and build the centre's psychology area elicited happiness and peace in me. Without trying, I was organically arriving at a place where I could contribute to making psychotherapy accessible for people with sight loss in the rehabilitation centre where my mother (and I) couldn't get it. I feel like I can finally close the circle and repair in others what I couldn't address as a child with my mother.

This is an ongoing project through which I am training the psychologist and creating a protocol to work through the emotional impact of sight loss, adjusting Mhairi Thurston's grieving model and therapeutic approach for people with sight loss (Royal National Institute of Blind People, 2013; Thurston, 2010) in the Mexican population. Additionally, and working with this psychologist, we are building the inclusion area of the centre, aiming to promote access to education and jobs for people with blindness and visual impairments.

Conclusion: acceptance and reconceptualisation

It took me 25 years to arrive at this point. Setting up the psychology area in the centre that helped my mother and me learn Braille is coming full circle. I made it. I have completed my life's purpose. My mother can rest in peace now, and I can rest, accepting I couldn't help her, but through my experience with her, I got to offer the help I couldn't give her to others in her situation who might find it useful.

Growing up, I became the mother of my mother. Marilyn and Lita's love taught me how to love and be loved and cared for as a daughter. They provided a holding space that allowed me to work through my development and shape the woman I am today in ways my mother couldn't or didn't live long enough to get the chance to. I want to believe my mother would be happy with their job. I know I am.

Acknowledgements

Many people helped me through this journey, and all of them have a special place in my heart. First, I thank my mother for giving me all the life and love she could, as well as resilience and drive beyond my imagination. My life project is a tribute to her. Thank you, Marilyn Charles and Lita Crociani-Windland, for giving me your mother's love, with everything it implies. Thank you, Jesus García, for becoming a father to me. And thank you, Bruce Charles and Nigel Williams, for caring for me as a father would. Sophie Savage, Marycarmen Tamez, Ana Karen Flores, Samantha Gaspar, Karla Zarate and Anna Basora, thank you for walking beside me every step of the way. And thank you to the

many people I have crossed on the path who gave me light through the journey. I hope I was able to give back some light for your way as well.

Conflict of interest

The author declares that there is no conflict of interest.

References

Allen, M. (1989) The meaning of visual impairment to visually impaired adults, *Journal of Advanced Nursing*, 14(8): 640–6. doi: 10.1111/j.1365-2648.1989.tb01606.x

Charles, M. (2004) *Learning from Experience*, New York, NY: Analytic Press.

Freud, S. (1966 [1914]) Mourning and melancholia (1914), *The Standard Edition of the Complete Psychological Works of Sigmund Freud, vol. XIV (1914-1916): On the History of the Psycho-Analytic Movement, Papers on Metapsychology and Other Works*, London: Hogarth Press, pp. 237–58.

Hayeems, R., Geller, G., Finkelstein, D. and Faden, R. (2005) How patients experience progressive loss of visual function: a model of adjustment using qualitative methods, *British Journal of Ophthalmology*, 89(5): 615–20. doi: 10.1136/bjo.2003.036046

Lampl, A.W. and Oliver, G.W. (1985) Vision without sight, *Journal of Analytic Psychology*, 30(3): 297–309.

Loja, E., Costa, M.E., Hughes, B. and Menezes, I. (2012) Disability, embodiment and ableism: stories of resistance, *Disability & Society*, 28(2): 190–203. doi: 10.1080/09687599.2012.705057

Oyarzabal, C. (2006) El mundo 'visual del ciego', *Psyche Navegante 75* [online]. https://docplayer.es/18716327-El-mundo-visual-del-ciego.html

Royal National Institute of Blind People (2013) Group framework for emotional support, http://www.vision2020uk.org.uk/rnib-group-framework-for-emotional-support.

Sandoval, H., Pérez-Neri, I., Martínez-Flores, F., Del Valle-Cabrera, M. and Pineda, C. (2016) Disability in Mexico: a comparative analysis between descriptive models and historical periods using a timeline, *Salud Pública de Mexico*, 59(4): 429–36.

Thompson, L.M. (2017) *La Muerte en Vida: Algunas Reflexiones Sobre el Duelo en la Invidencia Adquirida*, Master's Dissertation: Universidad de Monterrey.

Thompson, L.M., Salinas, M., Herrera, H., González, S. and Contreras, D. (2013) *Proceso de Adaptación en Personas Invidentes A Causa de un Accidente o Enfermedad*, Bachelor's Dissertation: Universidad de Monterrey.

Thurston, M. (2010) An inquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted people, *Counselling and Psychotherapy Research*, 10(1): 3–12. doi: 10.1080/14733140903492139

Thurston, M., Thurston, A. and Mcleod, J. (2010) Socio-emotional effects of the transition from sight to blindness, *The British Journal of Visual Impairment*, 28(2): 90–112. doi: 10.1177/0264619609359304

Tuttle, D. and Tuttle, N. (1996) *Self-esteem and Adjusting with Blindness*, 2nd edn, Springfield, MO: Charles C. Thomas Publisher.

Winnicott, D.W. (1971) *Playing and Reality*, London: Routledge.

9.7.2 Domínguez-Varela IA, Aguilera-Partida JA, Dalvin LA, Garza-Garza LA, Thompson-García, LM, Barbosa-Quintana A & Ancona-Lezama D. (201). Retinoblastoma in an older Hispanic child masquerading as pars planitis: A case report. *European Journal of Ophthalmology*, 32(3): 71-74. DOI:10.1177/1120672121994487

Case report

EJO European Journal of Ophthalmology

European Journal of Ophthalmology
1–4

DOI: 10.1177/1120672121994487
journals.sagepub.com/home/ejo
SAGE

Retinoblastoma in an older Hispanic child masquerading as pars planitis: A case report

Irving Armando Domínguez-Varela[1], Jorge A Aguilera-Partida[2], Lauren A Dalvin[3], Lucas A Garza-Garza[1], Leslie M Thompson-García[4], Álvaro Barbosa-Quintana[5] and David Ancona-Lezama[1]

Abstract

Introduction: To report a case of a Hispanic girl with late-onset Retinoblastoma (Rb) who was misdiagnosed as a pars planitis prior to referral. Nearly 95% of all Rb cases are detected before age 5, and this patient was 8 years-old.

Methods: Case report of a late-onset Retinoblastoma with anterior chamber (AC) involvement plus the presence of an Ahmed valve. The patient had a history of a couple of months of topical therapy comprising medication for glaucoma, systemic steroids, and a filtration surgery (Ahmed valve), after that a biopsy was performed prior to referral. Upon arrival at our clinic, we performed an examination under anesthesia (EUA) and a B-scan ultrasound (US).

Results: Unilateral Retinoblastoma with an Ahmed valve in an AC filled with Rb seeds was diagnosed with the EUA and US in the left eye. An orbital exenteration with map biopsies of the left orbital cavity was performed with confirmation by histopathology of a poorly differentiated endophytic retinoblastoma with Bruch's membrane invasion. Follow-up sessions were then arranged as well as subsequent systemic chemotherapy cycles.

Conclusion: Given the rare incidence of retinoblastoma in children older than 5 years old, it can be easily mistaken for other differential diagnoses and treated with filtration surgeries that could put the patient's life at risk. In this report, late-onset Rb diagnosis is highlighted as a differential diagnosis in children and adults with atypical uveitis, which required a multidisciplinary approach.

Keywords

Eye, retinoblastoma, Ahmed valve, pars planitis, differential diagnosis, late-onset retinoblastoma

Date received: 12 August 2020; accepted: 14 January 2021

Introduction

Nearly 95% of all retinoblastoma (Rb) cases are detected before age 5.[1] Despite a few reports in older children and even adults, Rb's mean age of presentation remains 18 months.[1,2] While leukocoria is the most frequent presenting sign in children younger than 5-years-old, late-onset Rb usually presents with atypical findings, often masquerading as other conditions, including uveitis, endophthalmitis, and others.[2] Therefore, late-onset Rb tends to present with more advanced disease, often requiring enucleation.[1]

Herein, we present the case of a girl with late-onset Rb who was misdiagnosed as pars planitis prior to referral, and subsequently treated with steroids and filtration surgery by her primary ophthalmologist, thus posing a dangerous threat for extraocular dissemination and death. Retrospective case analysis is focused on identifying possible ways to distinguish late-onset Rb from simulating conditions.

---

[1] Ocular Oncology Service, Institute of Ophthalmology and Visual Sciences, Tecnologico de Monterrey, Monterrey, Mexico
[2] Ophthalmological Clinic, Santa Lucía, Guadalajara, Jalisco, Mexico
[3] Department of Ophthalmology, Mayo Clinic, Rochester, MO, USA
[4] University of the West of England, Bristol, England
[5] Pathology Service, San Jose Hospital, Tecnologico de Monterrey, Mexico

Corresponding author:
David Ancona-Lezama, Ocular Oncology Service, Institute of Ophthalmology and Visual Sciences, Tecnologico de Monterrey, Batallon de San Patricio 112, Monterrey 66278, Mexico.
Email: davidancona@medicos.tecsalud.mx

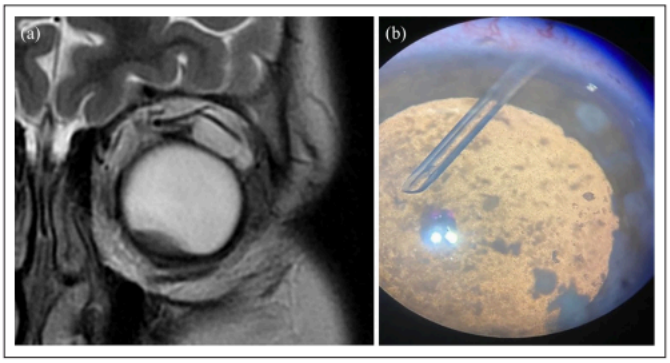


Figure 1. An 8-year-old Hispanic female with presumptive pars planitis in the left eye (OS) was treated with an Ahmed valve implant by a referring primary ophthalmologist due to poor intraocular pressure control. (a) The magnetic resonance (MRI) showed a T2 intraocular hypointense mass in the left inferonasal quadrant, and an Ahmed valve placed in the supratemporal quadrant. (b) On examination under anesthesia (EUA), the anterior chamber was filled with pseudohypopyon consistent with retinoblastoma seeds, in the presence of the valve tube. Flow of microscopic seeds through the tube were evidenced at the time.

Case description

An 8-year-old Hispanic female with no past medical history and no family history of retinoblastoma, presented with painless leukocoria in her left eye (OS) of 3 months duration. She was taken to a general public hospital where presumptive pars planitis OS was diagnosed. Intraocular pressure (IOP) was registered at 12 mmHg in the right eye (OD) and 60 mmHg OS. On examination OS, profuse inflammatory cells of the anterior chamber and vitreous were observed. Not knowing the diagnosis, the treating ophthalmologist suggested an intraocular fine-needle aspiration biopsy (FNAB), along with the initiation of topical glaucoma drops: Dorzolamide 20/timolol 5/brimonidine 2 mg/ml, Acetazolamide 250 mg, and Brinzolamide 10 mg/Timolol 5 mg/ml. Unfortunately, the biopsy came back insufficient. Furthermore, a B-scan ultrasound (US) failed to identify any presence of tumor or calcification. This prompted the treating physician to start management for an inflammatory condition with oral prednisone (40 mg daily).

One month later, IOP OS remained elevated at 60 mmHg, despite topical treatment. Additionally, the previously healthy OD registered an IOP of 50 mmHg, requiring initiation of topical glaucoma treatment. This recalcitrant ocular hypertension once considered to be secondary to inflammation, was now thought to have worsened due to steroid use. Given the poor IOP control, an Ahmed valve was implanted OS, and the patient was later referred to a uveitis specialist (JAP) due to poor control. The uveitis specialist identified anterior chamber (AC) pseudo-cells that resembled Rb seeds, prompting gradual reduction of systemic immunosuppression and urgent referral to our ocular oncology clinic.

Upon arrival at our clinic, best-corrected Snellen visual acuity measured 20/25 OD, and 20/70 OS. IOP was measured at 30 mmHg bilaterally. The rest of OD examination was normal. Anterior segment examination OS revealed mild ptosis, conjunctival hyperemia, mild corneal edema, and more importantly, coexistence of an Ahmed tube in a seed-filled AC (Figure 1). Dilated fundoscopy OS revealed a white tumor inferiorly from 6 to 9 o'clock in the far periphery with vitreous seeding. Due to AC involvement, this tumor was marked as group E, according to the International Classification of Retinoblastoma (ICRB).

Extensive examination and systemic metastasis screening were performed by our pediatric oncologist, including complete blood count, lumbar puncture, bone marrow biopsy, and brain magnetic resonance imaging (MRI). Fortunately, bloodwork, cerebrospinal fluid cytology, and bone marrow biopsy were all within normal limits. MRI demonstrated a T2 hypointense mass in the left posterior segment inferiorly with an Ahmed valve in the temporal quadrant (Figure 1(a)). No signs of extraocular extension, optic nerve infiltration, or brain metastases were observed on MRI. A conscientious examination under anesthesia (EUA) was performed where AC seeds were observed, (Figure 1(b)) and US confirmed a tumor measuring 7.5 mm × 15 mm with intrinsic calcification and peritumoral vitreous seeding. This case was classified as stage IIIa. according to the International Retinoblastoma Staging System (IRSS), considering that the Ahmed valve facilitated the passage of intraocular seeds into the subconjunctival space.

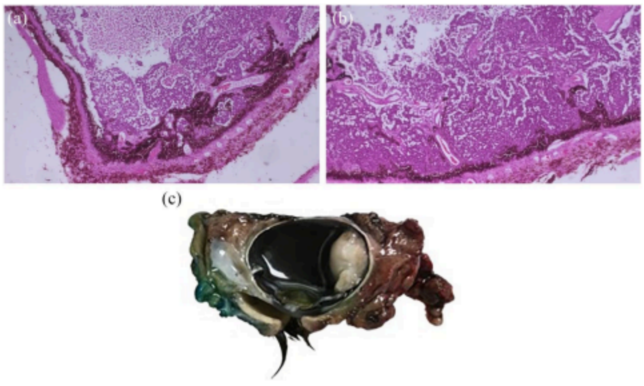


Figure 2. An 8-year-old Hispanic female with presumptive pars planitis in the left eye (OS) was treated with an Ahmed valve implant by a referring primary ophthalmologist due to poor intraocular pressure control. Despite good visual acuity, a careful orbital exenteration with map biopsies of the orbital cavity was performed. Micro/Macro section. (a) Sub-retinal space with infiltration in absence of choroidal invasion. (b) Ahmed valve subconjunctival space without local invasion. (c) Sagittal sectioning of the exenteration specimen between 11 and 7 o'clock positions depicting anterior inferior location of retinoblastoma mass.

Despite good visual acuity, the presence of an Ahmed valve in the setting of AC-involving RB necessitated extensive surgery for the safety of the child's life. Following parental consent, a careful orbital exenteration with map biopsies of the orbital cavity was performed. Histopathology analysis confirmed the clinical suspicion of a poorly differentiated endophytic retinoblastoma with Bruch's membrane invasion. No choroidal or optic nerve invasion (Stage pT1, using AJCC) was observed. (Figure 2) The decision to proceed with six cycles of high-dose intravenous chemotherapy was undertaken in order to prevent metastases. Due to financial constraints, the family was unable to perform the suggested genetic analysis for RB1 gene mutation.

As part of the multidisciplinary treatment, the patient and her family underwent psychodynamic psychotherapy. Follow-up sessions were then arranged around the exenteration procedure and subsequent systemic chemotherapy cycles to provide targeted anxiety management. Informed consent was obtained to publish clinical images, the report was approved by the Ethics and Research Committees of our institution in compliance with the tenets of the Declaration of Helsinki.

Conclusion

Late-onset retinoblastoma is atypical in both frequency and clinical presentation. Therefore, misdiagnosis of late-onset Rb is common and can lead to poorer prognosis.[3] In 1969 Stafford et al.[3] reported 15% of cases were misdiagnosed; thankfully, recent reports estimate the current rate of misdiagnosis under 5%. Current diagnostic tools and high clinical suspicion could have played an essential role in this improvement.

Pars planitis is a subset of Intermediate Uveitis (IU), in which snowbanks or snowballs are prominent features and there is no associated systemic or infectious disease. Represents 1%–26% of all cases of Uveitis, with a mean age at presentation of 23–31 years, which differs greatly with the age of this patient. IU is typically a bilateral disease with a chronic, slowly progressive course and episodes of relapses. The most common symptoms are blurred vision and floaters and not leukocoria like in a Retinoblastoma. The diagnosis of Pars planitis is based on history and examination and ancillary tests to exclude other diseases. Gold standard for the diagnosis of Retinoblastoma is made by an examination under anesthesia (EUA) and biopsies are contraindicated regardless of the circumstances.[4]

Since Rb is a less cohesive tumor, inadvertent intraocular surgery (Ahmed valve) or even FNAB allows for spread of intraocular tumor to the orbital space, increasing the risk for morbidity and mortality.[5] Although exenterating an eye with 20/70 vision could be considered controversial, the consensus among some Rb experts is that the presence of an Ahmed valve in an AC filled with Rb seeds could be considered extraocular invasion (IIIa by IRSS), given the potential free passage of seeds into the subconjunctival space. Therefore, we believe that although the histopathology analysis classified the specimen as stage pT1, considering a more advanced staging was prudent given the previous filtrating procedure, always prioritizing life before globe salvage. For example in India, eight patients (57%) out of 14 died after an inadvertent intraocular surgery in children with unsuspected retinoblastoma because of progressive disease despite initiation of treatment.[5,6] In this case, subconjunctival seeds or extraocular invasion were not encountered in the histopathology specimen, despite intentional search. Perhaps Rb seeds did not survive or were not included in the path specimen. However, given the high risk of hematogenous dissemination, high-dose intravenous chemotherapy was still indicated to prioritize life. It could become possible in the future to eventually discern between the presence or absence of extraocular microscopic invasion that could support globe salvage measures, to avoid exenteration in cases of suspicion.

In this case, we did not consider external beam radiotherapy (EBRT) due to its secondary effects, mainly increased mortality (53%) from second primary tumors in the field of radiation. As with every Rb survivor, long-term follow-up is warranted.[6] The follow-up will likely include repeated MRI in 6 months and every year afterward, along with complete physical exams by the pediatric oncologist to closely monitor for systemic chemotherapy side effects and local and distant metastases. Lastly, it is well documented that people struggling with an eye condition can present emotional distress such as anxiety, worry, uncertainty about the future, shock, and grief, among others. Custom follow-up is warranted in this case in order to achieve adequate grief management for the family.

This case report summarized the difficult clinical decision of exenterating a previously misdiagnosed, glaucomatous seeing eye. Despite modern advancements in globe salvaging therapies, the primary goal of the ocular oncologist still remains to protect life, followed by saving the globe and optimizing vision, only if safe. Thus, deciding on a life-saving technique is never questionable. In this specific case, salvaging the globe could pose a risk to the child's life, in an eye that had previously undergone two penetrating procedures increasing the probability of extraocular extension through microscopic orbital dissemination.

Late-onset Rb must be considered in the differential diagnosis of children and adults with atypical uveitis. We consider that a rise in intraocular pressure in this age range should also prompt a thorough examination prior to proceeding with any invasive procedure. Likewise, we suggest referral to a qualified ocular oncology service in suspicious cases and defer care to an ocular oncology specialist before making any procedure.

Informed consent

We thank the patient's mother for granting permission to publish this information.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iDs

Irving Armando Domínguez-Varela https://orcid.org/0000-0002-2575-9334

Lauren A. Dalvin https://orcid.org/0000-0001-9710-4284

David Ancona-Lezama https://orcid.org/0000-0003-2748-9048

References

1. Kaliki S, Shields CL, Gupta A, et al. Newly diagnosed active retinoblastoma in adults. *Retina* 2015; 35: 2483–2488.
2. Karcioglu ZA, Abboud EB, Al-Mesfer SA, et al. Retinoblastoma in older children. *J AAPOS* 2002; 6: 26–32.
3. Stafford WR, Yanoff M and Parnell BL. Retinoblastomas initially misdiagnosed as primary ocular inflammations. *Arch Ophthalmol* 1969; 82: 771–773.
4. Yanoff M and Duker J. *Ophthalmology*. 5th ed., https://www.elsevier.com/books/ophthalmology/yanoff/978-0-323-52819-1 (2018, accessed 25 October 2020).
5. Kaliki S, Taneja S and Palkonda VAR. Inadvertent intraocular surgery in children with unsuspected retinoblastoma: a study of 14 cases. *Retina* 2019; 39: 1794–1801.
6. Ancona-Lezama D, Dalvin LA and Shields CL. Modern treatment of retinoblastoma: a 2020 review. *Indian J Ophthalmol* 2020; 68(11): 2356–2365.