Becoming my mother's eyes

Leslie M. Thompson, MSc

University of the West of England, England
Maccia, Mexico

Abstract:

Linking the person and the society, psycho-social 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 paper 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 to 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.

Keywords

Sight Loss
Psycho-social Studies
Social Model of Disability
Psychoanalysis
Mother- Daughter Relationship

Word count:

4,921

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 that became mother figures for me. They repositioned that 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 5. My father decided my mother's sickness was too much for him and left. Being an only child, the responsibility of 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 a neighbour's house (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, feed and dialyse my mother, go to sleep, and wake up at least three times a night because she wasn't feeling well and she needed either an insulin shot, pain medication, to throw up, or all of the above.

But why was a 5-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: (1) the charity model identifies disabilities with imperfections, impurities, gods' 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. (2) 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 useful given the tools to rehabilitate and integrate. (3) The social model proposes that disability results from a society designed to meet only the needs of "normal" people. Even though they're roughly located through time, these models are still present today (Sandoval, H., Pérez-Neri, I., Martínez-Flores, F., Del Valle-Cabrera, M. & Pineda, C., 2016).

Neither of us had a job, so we lived from any help my family or my mother's friends would give us. My mother's siblings helped us 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 of 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 jail, 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 she 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), 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. I would constantly renounce eating to secure she had something to eat tomorrow.

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 more 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 learned how to cry without making any noise. I became not only her eyes but 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. "Yeeeeeees," she said. I signalled the paramedic. They turned on the siren. 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, Costa, Hughes & Menezes, 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 and reflecting 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 upon 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, Costa, Hughes & Menezes, 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 toward 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 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; Hayeems et al., 2005; Thurston,2010; Tuttle & Tuttle,1996). I was particularly interested in the model Mhairi Thurston (2010) developed because it was the only one that addressed the need to renounce the 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, 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 (Author’s own et al., 2013).

What caught my attention was that when the colleagues I was doing this research with and me arrived at the rehabilitation centre, they told us that the participants were already adapted to blindness and that interviewing them about their grieving processes was a waste of time. We interviewed them anyway.

The participants talked about their difficulty in the adjustment process, 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" (Authors own et al., 2013, pp. 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 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 program 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 and read a bit more. I started working at the University of Monterrey (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 program as part of my job. My boss was the program 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 program with international links, so I invited Dr Marilyn Charles, who I met at a conference from the American Psychological Association to become a visiting professor. Since then, she started travelling to Mexico and teaching seminars throughout the program. 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 one of my dearest friends until today. With her guidance, I learned 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, 1917) 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 & 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 BA degree to deliver my Master's thesis as the answer to why emotional support was needed in the adjustment process of sight loss. 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 question: 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 into the international realm. 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 Psycho-social 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 Psycho-social studies at the University of the West of England, Lita's programme. I had never talked with Lita.

At the following year's conference, Lita approached me and said 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 exam, 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. "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. She would welcome me to stay in her house through the PhD programme. Lita 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 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 psycho-social perspective, using a psychoanalytic lens and the theoretical bases of the social model of disability. It's 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 the Blind 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've 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 sight, and I believe it's 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 learned 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'm 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 (2010) in the Mexican population. Additionally, and working with this psychologist, we're 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 reconceptualization

It took me 25 years to arrive at this point. Setting up the psychology area in the centre that aided my mother and me learn Braille is coming full circle. I made it. I have completed my life's purpose. My mom 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 that 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 enough to get the chance to. I want to believe my mother would be happy with their job. I know I am.

References:

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]

Charles, M. (2004). Learning from Experience. New York: Analytic Press

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]

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]

Oyarzabal, C. (2007). El mundo "visual del ciego". *Psicoanálisis y Discapacitados.* [online, accessed 6 October 2019]

Royal National Institute for the Blind (2013). Group Framework for Emotional Support. *Royal National Institute for the Blind.* [online]. Available from: http://www.vision2020uk.org.uk/rnib-group-framework-for-emotional-support/ [Accessed 14 February 2021]

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]

Author's own. (2017). *La muerte en vida: algunas reflexiones sobre el duelo en la invidencia adquirida.* Masters, Universidad de Monterrey.

Author’s own, 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.

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.).* Springfield: Charles C. Thomas Publisher

Winnicott, D.W. (1971). *Playing and Reality*. London: Routledge.

Conflict of interest statement: The author declares that there is no conflict of interest.

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've 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.