

How to build a Life History?

What can I use to compose the story? How to analyse participant narratives? How to present the reader with the final draft of the Life History?

Inspired by the experiences of the author Anabel Moriña, this book addresses the main doubts and longings of researchers who wish to explore the exciting journey of (re)constructing stories and highlighting voices, especially those who have them silenced by society, through attentive, sensitive, scientific listening.

With this purpose, the authors tell the impacting story of Beatriz who, after suffering a brutal assault, is faced with blindness at 28 years of age. The reader can follow and be moved by this construction, get to know the roles played in which researchers and participants maintain an attitude of equality, mutual collaboration, respect and proximity, which makes this method essential for the explicitness of trajectories of struggles and confrontations.

# Life History in Qualitative Research: the case of Beatriz

Ana Paula Ribeiro Alves Nilson Rogério da Silva

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## Presentation

Already in the master's study, completed in 2018 (ALVES, 2018), the Life History method aroused great interest and, in fact, it was the methodological path chosen and followed with some difficulties, but also with rich learning experiences. The Life History method carried out at the time with two participants with intellectual disabilities underwent methodological adjustments that considered their specificities and was inspired by Rosana Glat who, in 1989, used it with women with intellectual disabilities who elaborated on their lives at a time when it was not common to hear their voices (GLAT, 2009). Since then, the interest in the method has not decreased, rather, it has increased to the extent that the knowledge about other authors who have used it in different ways has also evolved, highlighting among them, Anabel Moriña (MORIÑA, 2016).

Life History is a method with the necessary depth to understand human conflicts, especially those that are silenced and remain at the margins of society. However, the richness of this method and the diversity of instruments that can be used to compose the life history is little known, which generates doubts about its performance, validity and scientificity. In view of this concern, still at the beginning of the doctoral course I attended the discipline entitled "TOPICOS ESPECIALES: Investigar con historias de vida en estudios con personas con colectivos vulnerable" taught by Professor Anabel Moriña, from Spain, which took place at UNESP/Marília in the second semester of 2019.

Anabel has experience and extensive knowledge about the different possibilities of the method. Her publications published in

Spain, where she lives, in the field of Special Education became a reference for this study, opening new paths and a new look for use in the collection for her doctorate, originating the text that gave life to this book, whose aim is to help researchers who want to appropriate and deepen their knowledge through listening to human life stories.

Based on this assumption, what we propose in this study is one of the different ways of researching with this method beyond the standard widespread model, with diversified instruments detailed herein. First, a brief presentation of the Life History method in qualitative research is necessary, as it is a promising field of application.

## **Preface**

Science has sought ways to better understand the human being, in a way that encompasses the richness of its behaviour and subjectivity. Various methods have been employed for this purpose, since the intention is to improve life conditions in society. Such attempts occur both in the individual sphere and in social processes and focus on the arduous mission of building a plural and universal society, which has as its foundation the respect and welcoming of different ways of thinking and acting in a common coexistence, seeking to legitimise the citizenship of all.

Qualitative studies are emerging on the scene and gaining new formats in investigations in the field of Human and Social Sciences in order to get closer to this commitment.

The Life History is brought to light, which has been configured as a robust methodological procedure to enable researchers to know in depth the trajectory of lives in a rather unique way. With this, there is the possibility of sharing experiences loaded with idiosyncrasies, allowing the researcher, in an intense joint dive, to investigate and unveil with property the narratives that date and mark the human subjectivity of the participants. In other words, it allows us to apprehend in the speeches the human movement in a particular way in its intensity. Making use of such a procedure makes it possible to identify and analyse these social processes.

This book is a surprising read, as it provokes a mixture of thoughts, anguishes, breaths, and reflections. In the pages that follow, the authors bring the richness of *Beatriz's* narratives, a woman

who abruptly becomes blind at the age of 28. From that date onwards, crossings occur in her life, implying considerable changes in the most diverse spheres.

How to talk about disability and its implications in a context marked by stigma and prejudice? Can life be interrupted and lived in another way, as if we died and were reborn into the same person? Does the rupture with who you were, with your friends, your work, your relationship with your family, your dreams, and fears cease to exist or start to be configured in another way? Would it be possible to have a new identity?

These issues, and many others, are brought up in detail, allowing the reader to act as a spectator of a life full of singular movements that imply the daily life of people with disabilities, allowing us to observe that, even after the enactment of a series of norms and policies deemed inclusive, it is clear that there is still a long way to go before we can get away from a position in which we have little respect for bodies and behaviours considered different.

The book presents us with an ethical and careful posture of the person conducting the research, with due concern to ensure attentive listening. Through the presentation of questions, it gives the participant the opportunity to revisit events and also to think about future actions, shifting the gaze from the self to the wider context during dialogic moments.

Gathered in the following pages, it is possible to find information about the procedure steps in the use of Life History and its adjacent instruments, which, in this case, bring a digression of what constitutes the *becoming* of a blind person, who needs to tread a new human constitution in such a challenging universe.

Lucia Pereira Leite

## Introduction

The qualitative approach brings out the relevance and materiality of the word of the individual, author of his experiences, memories and identity, becoming a powerful tool capable of entering the universe of identity, meanings, practical and everyday knowledge that permeate the relationships, which allows the identification and personal and cultural reconstruction of such experiences (BOLIVAR & DOMINGO, 2006).

The authors also add that it is through language that due relevance is given to the discursive dimension of individuality, how the human person experiences and means events of his/her life. In this sense, by telling their own experiences as a person with disability who lives in a given society, culture and time, who works, faces and adjusts to the standards, allows them to be interpreted and (re)meant, constituting a peculiar and promising perspective of investigation. According to Bolivar and Domingo (2006) this includes subjectivity as a necessary condition for social knowledge which, by means of a dialogue with oneself and also with the interlocutor, seeks the construction of new understandings and meanings about reality, beyond those imposed and obvious, expanding the narrative and dialogical "I" to the relational and communitarian nature.

This implies knowing how the person of a certain group, whose voice has been silenced by the dominant standards, behaves, reacts and lives within the social norms constructed for her/him. From this perspective, what Bolivar and Domingo (2006) called

cultural portrait is created in which through the subjective accounts of a person (representative of a group) one reflects on experiences, conflicts, values and daily life. This approach may also use the reports of other informants, who will compose a polyphony of voices, enriching the knowledge and understanding of the reality presented.

In this study, the qualitative research based on personal narratives was adopted as a principle through the Life History method, which aimed at valuing and including the subjectivity of a disabled person who experiences situations of stigma in society. Moriña (2018) lists the six main characteristics of this type of research, the first being the priority given to listening to the voices of people who are commonly silenced and excluded from the scientific discourse. It is emphasized that this voice assumes a protagonist role in research, since it is not spoken or researched *about* it, but it is spoken and researched *with* it. The participant has the right to be heard when telling experiences lived by him in his own words according to his perceptions and have his voice playing a leading role in the academic discourse.

The second characteristic occurs in the role of subjectivity, recognised and valued in the understanding of reality from the experiences of the person who narrates his/her life. The researcher needs to be faithful to the meaning that the participant gives to his or her life, being seen as an expert witness of the history reported, constituting an access route for others to know and interpret it according to the subjectivity of each reader (MORINA, 2017). In this strand, the role of the researcher is considerably rethought to actually include subjectivity and understand the experiences and situations that are told from another perspective. Thus, the participant is not reduced to just an object of study, disappearing in its personality.

Rather, this participant has life, voice, and participation that are recognised, and valued. Given this, their narrative may be placed in the academic text in first person, emphasising that we are not speaking for them.

The attentive listening to those who for a long time had their discourse disregarded intends to guarantee and value the subjectivity of the participant and requires a type of analysis that contemplates such choices, which refers to the third characteristic of the Life History method: the narrative analysis of the data. It is necessary, according to Moriña (2018) to contemplate the narratives in their entirety, without fragmenting them, since the analysis produces stories and seeks singular aspects of a life, revealing its unique nature. However, it is important to emphasize that the subjectivity of the participant will not be the only present, since that of the researchers will inevitably be incorporated into the interpretation and analysis performed, as will be detailed in a later topic.

Continuing, we come to the fourth characteristic that relates to the role of the narrator as an active participant and not just an object of the study. This type of relationship built between participant and researcher puts both in new roles rarely experienced in scientific research: the first assumes the protagonism and has his narrative valued as capable of causing social change and the second loses the traditional position of power of who alone takes the decision of how to conduct the interviews and analysis causing a change in the way the production of knowledge is understood. Thus, researcher and narrator are placed in a position of equality when intervening together in the study, making explicit the social acceptance when the narrator goes from object to active participant in a dynamic relationship of

constant learning and transformations between both (MORIÑA, 2018).

It is noted so far the democratic character of this type of research, which leads us to the fifth feature of the method: the emancipatory dimension in which it seeks to empower the participant to act in research. The intentionality is beyond the mere description and interpretation of the world, it seeks to cause social change through the narrative method, bringing the voice that previously inhabited the silence to act as an agent of social and personal transformation. This interview structure can cause discomfort by rethinking roles and concomitantly ensuring that both parties feel comfortable and close enough to share beliefs, experiences, vulnerabilities (MORINÁ, 2017; 2018).

From this perspective, the researcher is a channel for them to share their skills and abilities with a view to empowering the participant to also act and contribute throughout the process from collection to final disposal of the work, promoting their empowerment in research. The researcher also assumes a position of empathy through respectful listening to the participant's ability to explore and determine their limits and possibilities (MORIÑA, 2017). By assuming a new role and a new way of doing research, the researcher is disentangled from the traditional role of an expert interpreter, distant and impartial. When the role of the researcher is transformed, the role of the participant is also transformed and, consequently, can transform contexts around him/her, triggering the emancipatory process by questioning roles throughout society (MORIÑA, 2018).

In view of the five characteristics exposed above, it is pertinent to highlight the sixth one, which is a key element of everything that has been exposed so far: research ethics. According to Moriña (2018) ethics is the vital part and refers to how we should behave in relation to the person with whom we are interacting, a concern that should permeate the entire process of developing research.

Especially in research based on narratives, the ethical issue becomes complex and involves two different dimensions: procedural ethics and practical ethics (MORIÑA, 2018). The first refers to the legal procedures when it comes to research with human beings, i.e., about the Research Ethics Committee, being necessary its approval before starting the collection. The second dimension is related to the ethical tensions and conflicts that arise during the course of the research in the interaction with the participant, and these may be different in each study, phase, and context. The most common issues that may emerge in research with narratives are about the anonymity of the participant and about the information chosen for publication, since this may fulfil an inverse role of further stigmatizing the participant, which is obviously the opposite of what is desired.

In view of this synthesis of what the Life History method is, we appropriate and share the thought of Anabel Moriña (2017; 2018) who defines it as a type of research more in line with democratic, emancipatory and inclusive models and which enables greater involvement and proximity with the participant by not recognising him/her as a mere object to be studied, but as a person with an active voice, playing a leading role throughout the study. Thus, working with life history implies not only describing and interpreting, but transforming personal, social, human realities. However, it is not a simple path, being even more challenging when questioned in relation to scientificity, objectivity and representativeness, which leads the researcher to feel "swimming against the hegemonic tide"

(MORIÑA, 2018, p.11). From this perspective, we will explain in the following topics the paths that such methodological choice led to, as well as the difficulties, challenges, directions, and achievements.

#### 1.

# The Development of the Life Story

The field in which the Life History method has been used has been increasingly broad, encompassing researchers from various areas of knowledge, however, there are still doubts regarding the different ways of performing it, being important to know the model adopted in this study. Moriña (2017) clarifies the difference between *Life Story* and *Life History* since they are often confused, which leads to misunderstandings, including the validity of the method.

According to Moriña (2017) the *Life Story* is a biographical narrative that a person makes of his entire life or part of it through unstructured interviews in order to capture his perceptions, that is, the story of a life, the way the person tells it. The participant assumes a passive posture when narrating his or her life, but does not get involved with the way in which this information will be treated and the researcher is limited to stimulating the narratives and listening to them. In this model, the only source of information is the participant's account, which in turn is published without any editing, that is, without spelling or other corrections, preserving the linguistic characteristics of the narrator in the way it was transcribed.

Life History, on the other hand, is more comprehensive and includes the Life Story as one of the tools to reconstruct a story without, however, being limited to it. It is about reconstructing a story as it is experienced (and not just told) and the participant's account, the main source of information, may not be presented to the

reader in its literal form of transcription, but after edits that ensure a pleasant and understandable reading to the reader without, however, altering the meaning of what was said. When we mention edits, we mean spelling corrections for written language and contextualizations that may include other reports that complement parts of the participant's speech and also a new organization of everything that was said, aiming at a sequence and continuity that is sometimes lost in oral language. To (re) construct a story, it is therefore necessary to use other sources to complement and contextualize the account presented, such as documentary evidence, historical data, medical reports, interviews with other informants, photographs, texts, observations, among others, with the intention of enabling an intertextual and inter-contextual analysis.

In *Life History*, there is a change in the roles played by participant and researcher. The former changes from a mere narrator of his life to an investigator, participating actively in all research processes, for example, in decisions about how his story will be presented, what information will be published or not. The second also undergoes change when, in addition to simply listening and stimulating the narrative, it places itself at the service of the participant, enabling him to act and become involved with the textual and contextual construction of the research. In this perspective, the life story is constituted in the final text that reaches the hands of readers with all the processes of reconstruction, editing and participation, without, however, losing validity as long as it is clearly explained in the method of the study everything that was done.

It is possible that the researcher and participant build the life history in two ways: the entire life trajectory since birth or by the thematic life history in which we delimit cuttings of life in relation to a period or theme of their history that will be explored in depth, the latter being performed in the present study in which we will present the story of a person with disability in facing stigma. We then follow the steps for this construction.

The first step was the choice of how to work with personal narrative and the second of opting for a single life story and in-depth, respectively, in this order (PUJADAS, 2000; MORIŃA, 2017).

Narrative can be understood as the way of using language or another symbolic system to interpret life events respecting the temporal and logical order, establishing coherence between past, present, and future. The narrative is the representation that the participant makes of his life at a given time and context, allowing researchers to transform it into a life story through a methodological treatment in which it builds a new account in joint work with the participant (PUJADAS, 2000).

It is also up to the researcher to stimulate the participant in his narratives, guide him when there is any lapse in memory, and maintain the direction by the topic of interest. It is inappropriate to interrupt the narrative, but it is necessary to be sensitive to what is important to the participant and that needs to be said and respectfully listened to, even if not published. However, sometimes, from these unexpected and uninterrupted reports, themes emerge that become valuable and relevant information for research.

It is important that the interviews be preferably carried out in the participant's own home because memory is the central point of the narrator who can relive and revisit experiences with the help of photos, personal diaries, videos, objects, in short, support supports that take him/her to different contexts and times and that help him/her to compose his/her story.

Pujadas (2000) suggests that to outline the work, the researcher creates four files that ensure the completeness of each interview session, leading the same to explore, comprehensively, every aspect of the narrated story. They are "Literal, Thematic, Chronological and by Persons", this implies that in each interview, the account will be transcribed and organized in these files: first the *literal* record of the interview sessions that the researcher performs with the participant; then, the fragments referring to each title cited as emerging themes – *thematic*; the order in which the facts happened – *chronological*; and the people mentioned by the narrator, allowing the researcher to realize before the next interview, possible lapses and discontinuities that can be filled – *people*.

When starting the new interview, the researcher should revisit with the participant by means of written text or excerpts from the transcript the main aspects covered in the previous conversation, which shows all the commitment and interest in what is being said, besides providing the participant with knowledge of the written form that their reports have acquired, also allowing them to comment, correct or add something if desired.

It is worth emphasising that the participant assumes a position of co-author of the work constructed, being the main figure in the whole process. Being a co-author includes, among other things, having the right to choose the very image that is being built through their accounts and that will be made public. Thus, the participant will need to recognise himself in the transcriptions of his narratives and may not accept the literal form of transcription with the common mistakes and vices typical of oral language, but prefer that there be a correction to the standards of the written language. This does not mean that the meaning and content of what he said will be altered in

any way, but only that care is taken to respect the participant's desire to avoid exposure and the non-recognition or embarrassment of what was transcribed.

In addition, the care taken in not publishing the report without prior corrections is due to the fact that if we did so, we could further reproduce the stigma towards the disabled person. In this sense, the verbatim transcript stored in one of the four files is for the use of the researcher and will not be published without first going through an editing of the written language norms and the approval of the co-author (PUJADAS, 2000).

The second step was the choice of working with a single life story, that is, with a single participant. This choice is due to the fact that with a single participant, it is possible to dedicate time and depth, numerous and detailed interviews until the topic of interest is exhausted, and the story is (re)constructed, which is not possible with many participants. It is a mistake to consider that the representativeness criterion is given by the quantity of informants and not by the quality and depth of the discourse in development.

According to Moriña (2018), this type of approach requires the researcher and the participant to spend a lot of time together, at first gathering the data and then discussing the results, which is a slow, intense and deep process of involvement that requires several meetings. From this perspective, the researcher's sensitivity is necessary to perceive the moments to respect the personal space of the participant, such as medical visits, work, activities and personal problems that overwhelm him or her and make it impossible to be present at scheduled meetings, even if it results in the extension of the process of conducting and analysing the interviews.

Given the above, it is recommended that the research should be designed with small samples, which is an important characteristic that defines research with Life History. A single case or at most three participants would be desirable, since a larger number would not allow the necessary depth (MORINÁ, 2018; PUJADAS, 2000). It is emphasized that although there is a single protagonist, there is a polyphony of voices, i.e., other testimonies that accompany the voice of the protagonist of the study.

After the knowledge of what it is and how to work with narratives and with a single story, we come to the moment of building the "life history" itself. Building a single life story is far from being a simple process because it is necessary to find a participant who has the ability to develop a cohesive and in-depth discourse about his or her life, faithful to the events as far as possible (since it depends on memory and own interpretation of the facts) and critical enough to be a representation of all those who face the same circumstances. Thus, it is possible to realize that the choice of the participant becomes the key factor for the success of the construction of life history because he is the central figure of the study and on him will depend on all its path, since, however skilled the researchers may be, they cannot "create" history, being dependent on the way it is lived and told.

This does not mean that people with difficulties in expressing themselves should be excluded from research with narratives because although they require more strategies and instruments that assist them in the composition of their story, as an example, the use of photographs, extended time, interventions, among others, they can reconstruct stories that need even more to be told and heard (ALVES, 2018; MORIÑA, 2017).

Besides the choice of a participant who has the desire to narrate his experiences, it is necessary that he has the time available for the several and exhausting interview sessions that will compose his life story. This is perhaps one of the main challenges of the researcher, to keep the participant stimulated and involved enough so that he does not get bored and give up in the middle of the journey, does not lose confidence in his interlocutor, keeping him close enough to feel the desire to confide his life. There are also circumstantial obstacles that may emerge in this path and that are independent of the researcher and perhaps of the participant himself and may interfere or even interrupt the entire long process, but this will be detailed further on.

It is important to emphasize that the life story is, therefore, the final text that reaches the hands of the reader, resulting from all the edits and extensive processes through which the initial narrative with co-authorship of the participant went through. It is necessary for the reader to be aware that there are other ways of developing the method such as, for example, the style with micro life stories, in which there are several participants with parallel or crossed stories and the interviews are brief and conducted in a short period of time, rely on few instruments or only the report and can be collected by several researchers (PUJADAS, 2000; MORIÑA, 2017). However, we will stick in this book only to the single, in-depth life history model, which demands time, proximity and varied instruments.

It is noteworthy that the process followed for the editing of the life history involved classifying all the information in files in literal, thematic, chronological and people order; always resume the transcriptions before the next interview so that any lapse or discontinuity could be identified; use photos, texts, objects of the participant to compose the account of his story; share with the participant the written form that the work is acquiring in order to obtain his consent, criticism, correction, or suggestion; make adjustments in the writing of the accounts, minimal so as not to compromise their meaning and style, but sufficient not to embarrass the participant in the public image that will give of himself, ensuring the reader fluidity in reading, according to the suggestions of Pujadas (2000) and Moriña (2017).

In the construction of the story of this study in question, there was a combination of strategies with emphasis on the report of the participant based on her memory and interpretation of reality and also reports from family members, client, and teacher who contextualised/complemented and reconstructed the facts, as well as other instruments, printing different interpretations for the same situation, which will be explained below.

At the end of the life history, the researchers had the task of expressing their subjective interpretations of the narrated accounts. This implies reflecting on the systems and categories that society builds to stigmatize people with disabilities, on the participant's ways of coping and that put her in a position of struggle, often lonely. The struggle of the participant in question may represent the struggle of all people with disabilities stigmatized by society and provide opportunities for understanding, reflection and discussion on stigma.

Before we discuss the next topic, it is worth presenting a synthesis of the main choices that involved the outlining of the method used, highlighting that they are in Table I, below in italics and underlined.

Table I: Methodological choices.

	Number of histories:		
	✓ Multiple Reports (several participants)		
	Single report		
	Depth of data collection:		
T CT · C	✓ Micro life histories (with fewer instruments and		
Types of Life Histories:	interviews in a short period of time)		
	In-depth life history		
	Range:		
	✓ Complete life history (complete trajectory since		
	birth)		
	Thematic life history (focus on stigma)		

Source: Own elaboration, based on Moriña (2017).

#### 2.

# **Choosing the Participant**

In order to contextualize the reader, this chapter will present the participant who will illustrate the application of the method, as well as the reason for the theme addressed. The interest in talking about the topic of stigma arose from the Master's study (ALVES, 2018) in which we identified the importance of work for the human development of the research participants, two people with intellectual disabilities. It was found that work contributed to the differentiation of their trajectories, which contradicted what society commonly expects from people in their condition, i.e. the inability to work. However, it was possible to identify several situations in which work also contributed to their stigmatisation in the work environment, as well as to identify the presence of strategies that those participants used to deal with these issues, a subject that could not be covered due to the object of study defined for the master's degree.

After the master's study, the theme work continued to be an important criterion for the doctoral research, since this environment may facilitate the propagation of stigmas built about the abilities of the person with disability, and therefore it is of interest to know the strategies used when faced with the reality built by others about their identity (Goffman, 2008). According to Goffman (2008), the person with disability seeks ways to deal with stigma, and may withdraw and accept passively fulfilling the role expected from her or face it in an even aggressive way, causing reactions to this position. In the work

environment, as a result of face-to-face relationships, the social construction of their identity and the opportunity to (re)build their true identity are revealed.

The focus was on coping strategies created or provided in and by work, however, the life context of this participant was not disregarded, her previous experiences to work, disability and the way she experiences stigma, which certainly constituted her and contributed to the way she positions herself in the present, therefore, important for the understanding of who this person is.

In view of the above, the criteria that led us to choose the participant were: being a person with disability, regardless of whether congenital or acquired, and who developed some work activity. Moreover, we sought a participant with availability and interest in maintaining an active participation, for a long period and sometimes exhaustive. Thus, this is a convenience sample in which the participant involved was not randomly selected, but intentionally selected so as to meet the objective and criteria of the study. The knowledge of the history of the chosen participant happened through a common friendship that mentioned her as a possible candidate to meet the interest of the study.

We had only one participant, as previously explained, a 37-year-old woman, with blindness acquired at the age of 28, fictitiously named Beatriz preserving her real identity. Beatriz has a complete high school education and professionalization courses taken before and after the disability. She currently works as a massage therapist, a profession she chose after her disability.

In the first phase of the interviews, Beatriz lived with her parents and sisters, besides a very close aunt, in a house next to hers. In the second phase (the phases will be clarified further on) Beatriz

got married and changed residence, obtaining more privacy and comfort. In the new residence, she acquired more autonomy when she started cooking and taking care of the house independently, since she is alone during the day, the physical space also better met her needs when she got a room reserved and exclusive for her services to clients.

The participant was asked to focus on her adult life at work, especially because she understood that it is the environment that can propagate stigma the most, according to Goffman (2008).

Before getting into the object of interest of the study, which was her experiences as a person with disability dealing with stigmas about her, we needed to understand life as a person who did not deal with stigmas, difficulties, limitations arising from disability. Her life path was marked by a "before and after" and we sought to know the before disability in order to understand the after. In the first interview, therefore, we talked about life as it was lived without disability. From then on, we started conversations about a certain period of life, the thematic life history, as the participant experiences it.

Without further ado, it is important for the reader to know who Beatriz is and why she was considered for the study and, in turn, why she considered participating in the study. Beatriz was not only accepted by the researchers, but mainly, she accepted the researcher with whom she would maintain a close and trustworthy contact. As previously mentioned, until the age of 28, she was considered a normal person, without disability and followed her trajectory marked by work, dreams and plans until they were abruptly interrupted by an assault that resulted in her disability. In 2008, she was brutally attacked by a cousin who suffers from schizophrenia, who broke her

face in half with hammers, tearing out an eye, nose, breaking the bones of her face, which almost led her to death. Among other consequences, she lost her sense of smell, taste, part of her hearing and movement of her left hand, as well as her sight.

Besides the consequences already mentioned, Beatriz deals with another stigmatizing factor, the disfiguration of her face. Even going through several facial reconstruction surgeries, she doesn't have one of her eyes, and the other remains closed, once the eyelid fell on her. She has lost her eyebrows and her nose has been replaced, but without fulfilling its original function because Beatriz doesn't breathe through it and doesn't have the sense of smell. She has scars on her arms and legs which remind her of the appearance of burns due to the removal of skin for grafting her face. The forehead region presents a depression (sunken), consequent of the destruction of the bones, besides feeling a lot of pain in the face. He has lost facial expressions, complaining that sometimes people do not realize whether he is expressing feelings such as joy, sadness, or irritability.

According to Beatriz, her face scares people and, as a result, she tries to hide it by wearing glasses in large sizes, dealing doubly with the stigma, for not having the sight and for having an image that distances herself from the beauty standards built by society. Beatriz reinvented herself in all areas of her life according to her new identity and role in society, among them, her professional life.

After conversations with the person who mediated between us, we set up a meeting and Beatriz, from the start, showed herself to be solicitous and interested in participating. This first contact was somewhat informal, just to get to know her personally and make the first impressions about whether she was, in fact, the person we were looking for in the study. On meeting her in person, an interest in her

story was definitely born and on learning the purpose of the study, the desire to contribute with her story was born in Beatriz.

#### 3.

## **In-Depth Interviews**

The in-depth interview, also known as biographical interview, is one of the instruments used to compose the life story, but not the only one. However, it will be treated in emphasis for understanding it as the main instrument, the others will be explained in later topics. Working with open and in-depth interviews, i.e., without a script of structured questions, requires the researcher to stimulate the narrative of the participant so that he can elaborate it in a chronological, clear, detailed and reflective way about the events of his life leaving explicit his interpretation of these (MORIÑA, 2017).

The narrative of the participant must respond to the objective of the study and even if the participant has the freedom to speak freely about what he/she deems important, it is necessary to be cautious so that it does not completely detract from the theme of the study and lose its meaning for the research. Therefore, the importance of total concentration of the researcher on what is being said, the stimuli provided, the phrase that will trigger the narrative, the guidance when there are memory lapses, the sensitivity to identify during the conversation what needs to be deepened in the narrative and the right time to clarify doubts or encourage the deepening of something.

Working with the in-depth interview in this study had as a favourable and decisive factor for its development the specificities of the participant, who demonstrated since the first interview to be willing and able to narrate her life with a wealth of details and

reflections. However, the fact that the interview does not have a structured script of questions does not imply the absence of direction, of a theme, of a guideline. This implies having a clear idea of what is sought in each interview or expectations in relation to the dialogue that is presented to the participant by means of a single sentence or question that will guide him/her on what is expected of him/her in each session. With each interview, the participant moves forward in the chronological time of their life story by reminiscing and reconstructing with their narrative, as well as in the research topic of interest.

Before moving on, it is necessary to clarify how the construction up to the moment of the interview went. The first meeting was somewhat informal in which we did not mention the research, although the participant already knew of this intention. We arranged an afternoon coffee at her home in the presence of the person who made the link between us and her family. The fact that we were introduced through someone known and trusted by the participant may have facilitated our interaction and, therefore, the option to hold this meeting with the presence of the mediator.

We had a second meeting, again at her home, and then we talked about the research. I explained thoroughly about the study, explaining its objective, theme and how her participation would happen. I explained that there could be many sessions, that we would discuss painful subjects for her such as the day of the assault, that she would have participations and activities to add to the study and that she could withdraw at any time if she thought it pertinent. I also described the importance that her collaboration would have for the study. After these aspects were clarified, the participant immediately

expressed her desire to participate. However, I asked her to think a little more and to answer later on, and she did so.

After the two initial meetings, the collection began and the first interview and participation through narrative actually occurred. It is important to clarify that before the beginning of the collection that happened two months after the first contact, we maintained proximity by phone, establishing a bond and building a relationship of trust so that we would not be strangers at the time she would talk about her life.

In the first interview I asked permission to turn on the recorder and after consent I again explained the purpose of the study, how her participation would take place and the importance of it, asking if she would agree to collaborate. Again, the participant expressed her interest and authorised the recordings, which allowed me to obtain her verbal and recorded informed consent. Still on the first interview, we talked about her life before the disability, what she did, what her plans were, how she lived, what she worried about. This interview lasted two hours and thirteen minutes and the sentence which triggered the narrative was "I would like you to talk about your life when you did not have a disability". It is important to emphasize that the researcher in an open interview may ask questions when something is not clear enough or ask the participant to talk a little more about something to deepen it, without inducing answers. Strategies such as repeating something that the participant himself said also stimulate his narrative and show that you are attentive to what he says.

As there was already some proximity, her narrative happened spontaneously, as in a conversation, going so far as to forget the recording and tell intimate things of her life, which suggests that the maintenance of contact and attempt to build the bond before the first interview may have contributed to the interaction. The fact that at a certain moment, she had forgotten that the conversation was being recorded generated discomfort in the participant, which led me the next day to call and clarify again that only what was of her approval would be published. This consideration of her discomfort generated trust on the part of the participant, and in a clear and honest manner we gradually built a bond of trust and ethics.

Closeness and trust is a strong characteristic of the life history method and there may be times when the participant, taken by the emotion of his narrative, speaks more than he would like others to know, besides the researcher. However, the ethical issues in this method are beyond the consent document signed at the beginning of the research and the researcher has the sensitivity to respect the fine line between being faithful to the narratives and being cruel to the participant by publishing information that may later lead him to unnecessary exposure, embarrassment and even stigmas, and this is precisely what we seek to confront. In this way, even if "consented" through a document, it is necessary to have constant agreements, reviews, opportunities to continue or give up and above all, to maintain commitment to the person who narrates, considering him/her not as a mere object of research, as well as awareness that not everything that is said will necessarily be published.

At the end of the first interview, I asked her to choose the name by which she would be called in the study to keep her anonymity, since no one better than herself to know which would best represent her. "Beatriz" was the chosen name because, according to her, it is a sweet name and that she had always found beautiful, thus being able to represent her. We also agreed on the frequency of

our meetings, days, and times of the week, always respecting and adapting to her routine and availability. It was agreed that the meetings would take place once a week, in her own home, for an indefinite period of time, at 2pm on Mondays, with flexibility in case Beatriz had any commitments or indisposition. The days, frequency, times, and place were decided exclusively by Beatriz, since as a researcher, I was at her complete disposal.

A week after the first interview that took place in a calm and spontaneous way, we conducted the second one and this was a moment of great tension on both sides. In this interview, we would discuss the day when her life changed, which we named "The day of the assault" so that we could understand how Beatriz acquired the disability.

Before this tense conversation, I had already transcribed the first interview and prepared a text to recall the main aspects we had elaborated on the week before so that she could assess whether the researcher was understanding her, whether the information was correct, whether she approved of the writing. In this text, the main aspects discussed were contemplated, however, it also included the subjectivity of the researcher who selected points that impacted her more deeply, also bringing an interpretation of the same. It was read to the participant who, at the end of the reading, was surprised with the way it was, in her words, well understood and represented, stating that the researcher really understood what she intended to express, especially in relation to what she felt in certain situations. She was also reassured to note that the intimate subject she had spoken about in the previous meeting, and which had caused discomfort later on, had not even been mentioned in the text. She did not change or alter the information, and her satisfaction with the moment of reading was

evident. This reading instigated Beatriz's interest even more in the presentation of her life story, the processes she would go through and its final format. Beatriz asked questions, and we made agreements about the text, such as writing in the first person, the edits, placing it in a chronological order to facilitate the reader's understanding, the corrections, among others.

It was possible to realize that reading interpretative texts about her narrative could be an important instrument to be explored, once Beatriz felt respected, valued and surprised with the interest and care with everything that was said during the interview. In fact, the moment to read about what we had talked about became something Beatriz looked forward to in the following meetings in which she always praised, was surprised and moved. She listened to the reading attentively, in an almost absolute silence that was only interrupted when she smiled, cried or nodded her head in agreement, whispering something as if she were talking to herself. From a simple summary to remember significant topics of the transcription of the previous conversation, it became a kind of gift, reward, or stimulus for Beatriz who appreciated the texts about her life.

It was also important to set the mood for the subject that was to come. The trigger phrase was, "I would like you to tell me how and when you lost your sight. Would you mind remembering that day for me?". Beatriz spoke for two hours and forty-seven minutes without interruption. No stimulus was needed for her narrative, just an outstretched hand to touch her at the most difficult moment for her. Although it was clear that she could stop the conversation at any moment and that she didn't need to talk about what she couldn't or didn't want to, Beatriz didn't stop. She talked, got emotional, got scared by the thunder of the rainy afternoon and by the barking of

the dog that was lying under the table at our feet. She ended her narrative on an intense note when she brought out her emotions, while being highly impactful for the minute details with which she exposed the violence she had suffered.

This was the most important interview, not only because of its content, but also because it was the most difficult for the participant to revisit her fears and also for the researcher to conduct a moment of pain that would be decisive for Beatriz's continuity or not in the research. Recalling and reliving such a terrible day stirred her emotions, traumas, and feelings. After this interview, she went back to dreaming about the aggressor who could not even pronounce her name during the narrative and, as a consequence, started to avoid the researcher.

On the day scheduled for the third interview, she forgot her appointment, and although I called her at the gate of her house, called and sent messages on her mobile phone warning that she was at the gate, it was her father who answered and called her. On this day, I noticed she was distant, so I suggested we should postpone the interview, but Beatriz insisted on continuing until we finished it. I read the text from the previous interview in which she told about the assault, and it was a moment of intense emotion. Before the reading, Beatriz made sure her niece wasn't around, so she wouldn't hear her because of the violent content. When writing this text, specifically, there was a concern in not highlighting the aggression itself, which was minutely detailed by Beatriz, but the feelings, uncertainties, perceptions arising from it, making, as far as possible, the moment less fearful for the listener. The information about the third and next interviews were not described on that occasion so as not to extend

ourselves too much. The reader will find them further on, told by Beatriz herself in her Life History.

On the day scheduled for the fourth interview, Beatriz called a few minutes earlier and cancelled, without much explanation. We rescheduled it for another day, and again she cancelled, showing resistance. It was necessary to give the participant this time of two weeks without interviews, to respect her distance and silence, to understand that, at that moment, she could not talk about herself, even though I always emphasized that I was at her disposal to talk to her, even if not for the research, even if not with a tape recorder. They were days of tension for realising that the participant was in conflict and could give up.

When Beatriz felt comfortable enough for a fourth interview that would take place a fortnight later, there was a need to review her consent and choice to participate. Again, I asked if she really wanted to continue collaborating, even in the face of the last conversation and how it reverberated in her life. Beatriz answered that she would like to continue and that even though she had relived difficult moments, talking and reflecting on the subject was doing her good. I proposed that our meetings should be spaced more apart, every fortnight so as not to overburden her, but she preferred to continue with weekly meetings. I asked her if she would like to change anything in the dynamics of our meetings, to which she said no.

When she read the text of the last conversation she was moved by her own story and the way she was being understood, but she still felt distant, as if we were regressing in the complicity we had built up until then. It was then that I asked her to write her Self Report (which will be detailed in the next topic) about the reasons that led her to choose her profession and I sent her my own Self Report about why I was doing a doctorate so that she could know a little more about me. Beatriz called me days later saying she had read the Self Report and was thrilled to know me a little further and to be able to understand the dedication to research. From then on, our bond, commitment, and involvement with the research was growing, which led us to overcome the most difficult interview and also the obstacle that was still to come.

Thus, our subsequent interviews happened with the same ease as the first one, but with increasing proximity in which I could identify the meanings of every gesture, pause, sigh, and even when I would seek my hand placed at the table. In all there were six interviews and in each one Beatriz would ask about the progress of the research, about the transcriptions, about the writing, about what and how it would be published, and we would negotiate how everything would be presented. Beatriz approved the idea of speaking in the first person and asked me to correct any possible language mistakes in the text, although she expressed herself well and easily.

Table II: First interviews conducted

### 1ST INTERVIEW

**Duration:** Two hours and thirteen minutes

**Topic of interest:** What was life like before the disability.

**Trigger phrase:** "I would like for you to talk about your life when you did not have a disability".

**Participation:** Beatriz narrated her life since childhood, her teenage years, and her youth when she started working, remembering what her plans and dreams were.

Beatriz was tasked during the week to think of a name to protect her identity, and to choose an object that represented her life before disability.

#### 2ND INTERVIEW

**Duration:** Two hours and forty-seven minutes

**Topic of interest:** How did she acquire the disability.

**Trigger phrase:** "I would like you to tell me how and when you lost your sight. Would you mind recalling that day for me?".

**Participation:** She elaborated on the assault, describing everything that happened on that day and the following days. She told about the day, a year after the aggression, when she knew that she would, undoubtedly, no longer be able to see with the eye that was left. She recalled moments of pain, uncertainty, insecurity, and fear of what her life would be like. She described feelings of helplessness, revolt, hopelessness and also gratitude for being alive.

#### **3RD INTERVIEW**

**Duration:** Three hours and five minutes

**Topic of interest:** The changes in daily life and relationships after acquiring her disability.

**Trigger phrase:** "Could you talk about whether anything has changed in your life after losing your sight?".

**Participation:** Beatriz told about her daily difficulties, about the changes in her relationship with her family and friends, about people who distanced themselves and others who became closer after her disability, about the ambiguity of sometimes being treated as incapable and sometimes being demanded to have skills as if there were no disability.

She mentioned friends who started to ignore her when they meet her on the streets and on social networks, as well as people who do not make room for her to walk on the pavement with the guide, sometimes even knocking her down. She also shared moments in which she herself throws her cane to the ground in protest when she is abruptly diverted by those accompanying her so that she does not bump into others, questioning who should be diverted.

#### **4TH INTERVIEW**

**Duration:** Two hours and six minutes

**Topic of interest:** The way she is perceived by society, according to her interpretation.

Trigger phrase: "Today I would like to know how your social life is".

**Participation:** Beatriz recounted things she used to do that currently make no sense to her, also about leisure choices that meet her needs. She reflected on the change in her attitude towards society when she started to worry about issues that previously went unnoticed, as well as the change in society's attitude towards her after becoming a person with disabilities.

She discussed the ambiguity in the way she is perceived by society, which sometimes labels her as a "warrior", sometimes as "that poor thing". She also mentioned the lack of unity among people with blindness regarding the fight for their rights.

We agreed how and when we would do "A day in the life of Beatriz" which took place a week after the fourth interview.

Source: Elaborated by the author.

Always at the end of the meetings, I announced what we would talk about later so that her anxiety would diminish, and after we had a cup of coffee, moments in which we talked about everyday matters and about the researcher, talked about her family members and laughed which reaffirmed us equality of roles, trust, and proximity. Beatriz always knew that even if she said anything beyond what she wanted others to know, it would not be published, repeated or said by the researcher, even in our informal afternoon coffee conversations.

It is important to describe these details and difficulties to the reader so that they understand that they are possible and susceptible in in-depth interviews due to the degree of proximity, of coexistence, of time that participant and researcher spend together when reconstructing the history of a life, this proximity being one of the main characteristics of the method. In addition to weaving questions and collecting answers, there is an involvement, empathy, and the researcher deals with a fine line between exaggerated intimacy, proximity and sufficient trust, whose imbalance may interfere with the progress of the work. The nuances arising from the singularities of the life history method prove its democratic, inclusive and human character. Below, Table III presents the reader with a section of one of the texts read to Beatriz before the new interview:

### Table III: Excerpt text read before the third interview.

In the previous meeting, we discussed the object chosen to represent the whole phase discussed in the first interview. The guitar named Ariel brought back memories of good times in one of the best phases of a twenty-year-old girl, full of life and expectations. Ariel was forgotten for a while, until Beatriz brings it back, with all the childish joy and excitement. Ariel makes us think about words that motivate or, on the contrary, can bury desires or dreams. It was like that when her father told her that she wasn't good at it, that she should stop making annoying noises. After these words, Ariel was set aside, discouragement took over what before was experimentation and possibility, and, just like so, silence occupied the space that once belonged to tones, chords, song, singing, and music.

Then we talked about the day of the assault and mainly about the days that followed it. Beatriz begins by telling me that that day seemed ordinary, like any other. It was just another day when she woke up, cleaned the house, went to the supermarket, bought some bread. Another day that she used her computer, chatted with friends, answered a phone call, made plans and took a shower. A day that should have been like any other, but didn't end like this.

Something broke through all the normalcy of that day. A loud noise. A fright. An evil look. A brutal assault, no explanation, no deserving, no understanding of why, no possibility of defending herself. But that day was only the first of many difficult days, days of pain, days of fear, of insecurity, of not knowing whom to trust. The first of many days that are not normal in the life of a twenty-eight-year-old girl.

Beatriz, the fearful and quiet girl, the quiet and shy teenager, the young girl with friends, plans, and work, on one particular day, perhaps the worst of them all, buried all her dreams within herself. That day was the one day when she lost the last hope of carrying on a bit of the versions of Beatriz from before [...].

On that very day, at that very hour, the Beatriz I know today was born: strong, yet generous, capable of silencing her screaming, placating her anger, hushing her crying, disguising her pain simply so that her aunt could stop crying. So strong that she is capable of consoling when she should be consoled, of understanding the other and putting herself in their place, when in fact she should only be understood and let others put themselves in her place. Strong enough to reinvent herself every day, to make new plans, to live with a trauma without leaving sweetness aside. She has become strong, but has not become severe [...].

Many challenges would still arise in her path. How to deal with people who victimise themselves almost disrespectfully and trivialise the brutality she suffered? How to deal with people who blame her as if she had done something terrible enough to deserve what happened to her, as if she had offended or deceived the aggressor, as if the torturer could be the victim and the victim assumed the role of the culprit? How to deal with comparisons, as if it weren't challenging enough to become a person with a disability?

We talked about fears and helplessness. We discussed friends who have left and others who have come. We talked about how hard it is not being able to see herself, not having a picture of her own face. We laughed a little at some people's reactions to seeing her face. Today, we laugh about it, but one day this used to bother her. She cannot help but relive so many moments of pain and uncertainty in surgeries, hospitals, with doctors, nurses. Moments of such pain that it inevitably gave rise to the anger "Why?", "Why me?". But even without an answer to that question, she was able to calm herself by saying "Thank you, for being with me!".

We ended by talking about a very special person. We are talking about a saving angel. A seventy-nine-year-old angel, with a white head, slow steps, but capable of stopping an aggressor. A friendly and loyal person, who respected her autonomy, who praised her crochet, who trusted her niece so much that she would allow a bath at the most fragile moment of her life or a simple undoing of her bra strap. A person who sat beside her just to look at the horizon and who would not leave her in the dark even when she could no longer see the light, making a point of

turning on the lamps when it was getting dark. Preta was the type of person that we rarely meet in life, and with whom Beatriz had the privilege of living.

And so... I got to know a bit more about Beatriz!!

Is there any information you would like to expand or reiterate?

Source: Elaborated by the author.

Going back to the interviews, when we were more engaged and used to the usual commitment of the meetings, a historical context significantly marks our interaction and interview. The world is facing, at the time of this writing, a Pandemic (Covid-19). This is a respiratory disease caused by the SARS-CoV-2 coronavirus with high transmissibility and severity, being adopted the isolation in quarantine and, under this condition, as the safest option to preserve both the participant's and the researcher's safety, the decision was made to suspend the interviews. On March 23, 2020, our interviews were interrupted with the decree of the governor of the State of São Paulo for people to stay at home. How to go through a phase of social distancing when using a method that requires intense proximity to the participant? This was the big question that arose and needed to be overcome with strategies, just as was the crisis during the most difficult interview that focused on the assault.

Forty days after the last interview, Beatriz and I considered the idea of doing it by video call. However, it was necessary to consider Beatriz's specificities, her vision is through touch, her attention requires silence away from external noises. During the interviews we were alone, doors and windows closed so that nothing interfered with her reasoning and hearing and when she wanted to call the researcher for a dialogue, ask about something or simply find some comfort, she sought the back of my hand with the palm of hers

and found it always stretched out on the table waiting for her or at other times, her hand rested on my shoulders. I could see his signs of tiredness or discomfort when he stretched his back on the back of the chair and then, as a researcher, I knew it was time to stop. How would these details be perceived by a video call? How would Beatrice communicate with the researcher without touching her? How would we ensure that noises would not impair the dialogue?

We decided to wait for the end of the social distancing to resume the interviews, although we spoke daily by phone, messages on *WhatsApp* and e-mail. Beatriz was informed about the progress of the writing, even the readings, she read a published article authored by the researchers, she also worked on her life line that will be later detailed.

Five months have passed since our last contact in person and with the relaxation of isolation we resumed face-to-face interviews, but following safety protocols such as the use of mask, alcohol and a certain distance. During this period, Beatriz got married and went through a change of residence, experiencing new experiences, challenges, greater autonomy and independence.

In the professional area, Beatriz also expanded her skills during the time she was away from her patients, learning new techniques in an *online* course on Reflexology. To learn the contents of the course it was necessary to create strategies and count on the help of another person who visualised the movements, applied them to Beatriz, who in turn practised on the person. As a result of the new knowledge, she extended the massage period, adding new movements and using other instruments such as therapeutic stones, besides creating a more comfortable environment to be attended in a private room.

Despite the new format of relationship, more distant than the one we were used to, we found new ways to express the complicity between both of us and had greater privacy and silence necessary for dialogues. It was not difficult for us to pick up where we left off, since we remained active both in contact and in the involvement with the research throughout this period of distance, that is, close even though we were distant. As a demonstration of this closeness, Beatriz decided to fully present herself and, in a gesture of full trust and acceptance with her interlocutor, removed the glasses that covered most of her face. In Table IV below, we present a summary of the interviews conducted during the relaxation of isolation:

Table IV: Interviews conducted after relaxation of isolation.

#### **5TH INTERVIEW**

**Duration:** Two hours and forty-six minutes.

**Topic of interest:** The role of work in Beatrice's life and the relationships established in it.

**Trigger phrase:** "I would like for you to talk about your work, that which is important to you".

**Participation:** Beatriz begins her statement by telling us how much she missed her work during her isolation period and how much she had reduced the number of appointments, even with the relaxation.

She spoke about the training she received before disability and after disability, reflecting on the differences between ways of learning and understanding massaging as a process.

She told about the importance that work has in her life, especially in the psychological aspect, about how she deals with those who mark her for mere curiosity, about the reasons and the moment when she chose this profession.

She reflected on how disability could be considered as an advantage in her profession, specifically, and on how much more resourceful she herself felt by not seeing the body of the other with her eyes.

Beatriz closes her speech talking about the feeling that work gives her of being useful and helping others, when the opposite usually occurs in other areas of her life.

At the end of the conversation, Beatriz announced that she wanted to reveal her face, removed the large glasses covering it and introduced herself to the researcher.

#### **6TH INTERVIEW**

**Duration:** Two hours and four minutes.

**Issue of interest:** Do you identify situations where you have experienced stigma? And do you/ how do you cope with these situations?

**Trigger phrase:** "I would like for you to tell me if you have ever experienced stigma and how you reacted to it".

Source: Elaborated by the author.

# 4.

# The Instruments

The Life History method is endowed with several particularities that significantly differentiate it from others. One of these is the way in which the interviewee participates, which is why they are called "participants" or "co-authors" rather than "subjects" of the research. This implies that the person in fact will have knowledge of and active participation in the entire research process, including decisions such as how their story will be presented to the reader.

There was intense participation of Beatriz in several moments of this study, such as in the in-depth interviews, in the decisions about which information would be published, as well as the form they would take. Beatriz was informed about the whole process from the transcriptions to the final presentation and made choices such as speaking in the first person, having spelling corrections in her speech when passing it to the written form and aspects that could not be published. Besides these, the final edition of her life story was previously subjected to her consent and approval.

Beatriz participated in some selected instruments for the reconstruction of her story. These instruments were based on Moriña (2017; 2018) and aimed to raise the maximum knowledge and information about the participant's life story through different nuances, as well as to actively involve her in the reconstruction of her own story. The instruments chosen to outline this study will be

detailed below, highlighting that there are others; however, we restricted the explanation to those we consider appropriate to the context and objective of the present investigation. They are, respectively, in this order: A day in the life of...; Self Report; Life line, and Interview with other informants.

# A day in the life of

The first instrument carried out with Beatriz's participation occurred after the fourth interview and was our last personal contact before the decree of social isolation consequent to the pandemic. "A day in the life of..." is a data collection technique in which the researcher spends a day with the participant to learn more about their daily lives. It can be carried out in different ways, as there is no exact definition on how to carry it out, which can be adjusted according to the context and intentionality of each investigation.

From this perspective, researcher, and participant decide which version best meets the research objective without disregarding the availability of the latter. As an example, they may choose to spend a whole day together and having the researcher follow their entire routine, from the moment they wake up until the end of their day. Moriña (2017) states that this technique can adopt other forms, such as an interview about the participant's routine from waking up until falling asleep, which would already guarantee information about their daily life. If the option is to spend the day together, they can record the events through photographs and filming or simply records of the observations.

In his study on the difficulties and obstacles that students with disabilities encounter at university, Moriña (2017) along with the

other researchers who assisted in data collection, chose to monitor only the period in which the student spent at the university, either in the classroom or in other environments such as the library and cafeteria, in order to witness the obstacles that emerged, in some cases it was recorded through photographs in others only with observations, depending on the consent of each student. The author emphasises that regardless of the model adopted, the important thing is that it provides a deepening in the life of the participant so that it seizes the uniqueness and subjectivity, contemplating and understanding their life story as a whole through their daily acts.

In the case of this study, we again analysed Beatriz's context and specificity, as she lives and works in the same environment and coexists with other people (at the time this instrument was carried out). Spending a whole day with Beatriz would imply invading the privacy of the residents of the house such as parents, sisters, niece, and aunt. In this sense, we considered that it would be more interesting to accompany the period of her work, since this environment is also of interest to the research to understand how/if she faces the stigma.

However, Beatriz raised another issue that would again invade another's privacy, since she works with massage. Accompanying her working day would imply accompanying intimate moments of her patients, who would not feel comfortable with the presence of a third person. Adapting ourselves to the context of her life, we agreed that on the day scheduled for "A day in the life of..." the researcher herself would be Beatriz's patient and could thus get to know how her work is developed, how she builds the environment to receive her clients, what the interaction between masseuse and patient is like, for how long, the contact, the bond between both, what could or could not

be an obstacle or difficulty, among other things. To further detail how the massage occurs with other patients, we conducted interviews about the work.

So, "A day in Beatriz's life" took place in one afternoon when I was received as a patient and could experience every detail such as the welcome, the massage, Beatriz's commands, the way she knows the other's body without the aid of sight, the music she puts on for the moment, the way she organizes the space, the concern with the well-being of those being assisted, how she reacts to the unexpected, for example, when the massager escapes from her hands or the ventilator is not directed to the desired location, how she checks the payment, among several other situations that emerged. By experiencing a day at work, it was possible to understand how situations that can be stigmatizing emerge and later these observations complemented and contextualized the narratives about work and stigma. We did not consider it necessary to use technological instruments such as photos or videos; rather, the emphasis was placed on the lived and remembered experience. In this way, decisions about when and how "A day in the life of..." would be carried out were made together with Beatriz, respecting her context and needs.

To illustrate this, in Table V below we highlight a small section of the record of the instrument "A day in the life of...":

Table V: Observation log excerpt - "A day in the life of Beatrice"

Beatriz opens the gate to receive me, dressed in white, with an overlapped lab coat and her name embroidered, with tied hair and sunglasses. Her face transmits seriousness, being quieter than usual, and with few words, she leads me to the place where she will give me my massage. When I enter the room, she immediately closes the curtain and locks the door. The white stretcher is prepared just below the window,

there is instrumental music in the environment, a fan under a chair and some instruments such as a massager and creams on the sofa. Beatriz asks me to remove my blouse, lie on my side and inform her which side I have chosen to lie on. She also asks for absolute silence so that she may know my body with her hands. At first, she shows a certain anxiety in front of the researcher, perhaps because she knew that this day would be described in her Life History. The sunny day makes us feel heat in the closed environment, and Beatriz realizes that she has not positioned the fan properly. She apologizes and redirects the fan until she feels the wind on our bodies. During the massage, a rolling pin (massager) escapes from her hands and falls to the floor. Beatriz leaves it without showing any concern. As the minutes go by, she loses the initial anxiety and safely performs each movement, with a soft voice inviting me to move on the stretcher to contemplate all the points of the body.

During the whole massage process, Beatriz remains silent, and I do the same, respecting her orientation since it is the first time she is touching me, and she needs to concentrate to get to know me. Her movements are precise and attentive, she notices every detail and asks about them, touches points which were, in fact, sensitive and painful and explains the reasons for the tensions. She tells me about a small deviation in my spine, notices a herniated disc in my lumbar spine and makes some recommendations.

The massage, the music chosen, the instruments used lead to a deep relaxation and relief of the pains resulting from bad posture and tensions. The initial shyness on my part is soon replaced by a surrender to that moment, resulting from Beatriz's professionalism. Although tired by the process, Beatriz demonstrates satisfaction with the result and with the feedback, when I answer how I feel after receiving the massage.

[...] At the end of approximately two hours of massage, I make the payment and Beatriz decides to give a discount by returning me a note. I ask about how she knows if she has returned me the correct amount, and smiling, she says by the size of the note. She steps on the lost utensil (massager) and exclaims, "I found it!".

Source: Elaborated by the author.

# Self-report

This is a document in which the participant himself narrates in the first person about the aspects he considers important for the composition of his life story and research interest. According to Moriña (2017) this collection technique can be complementary to others used, providing relevant information at a time when the participant has the opportunity to weave a self-reflection about her life, in the context and time chosen by her and without the presence of the researcher. In this perspective, the participant may have as much time as he/she deems necessary for self-reflection and there is no page limitation for writing. The participant is guided on the topic of interest, but remains free to carry out his interpretation and meaning, imprinting his subjectivity and evaluating what he deems essential and necessary to inform. This document may contain essential information to know and build their life story.

Beatriz was asked to reflect on the reasons that led her to choose her profession and the importance of work, with the intention of understanding the meaning and space of work in her life. However, once again it was necessary to take into account the specific characteristics of the participant, as well as any needs she might have, and we thought together about the best way to write the Self Report. Typing a text is something that demands a lot from Beatriz, since she finds it difficult to work on a computer because she does not adapt to the conditions offered. We considered the possibility of writing the text on the mobile phone, via *WhatsApp*, which is the modality in which she finds it easier, but this was discarded by the participant herself, who would not have the opportunity to draft, correct or delete anything if necessary. This was discarded by the participant herself,

who would not have the opportunity to draft, correct or delete anything if necessary. I suggested she should record it on audio and finally, she decided to face the difficulty with the computer and type the Self Report, sending it to me by e-mail. Beatriz asked for help to a blind friend she met at the Association of the Visually Impaired and who, according to her, dominates the formatting program needed on her computer to type texts.

From the beginning she was determined to write the Self Report, claiming it would be interesting, but what worried her was how she would manage to write and send it (at that stage we were already in social isolation). It was striking that she did not ask her seeing relatives for help typing or sending it, preferring a friend in the same condition, perhaps because the Self Report was something confiding and intimate, an exercise of looking inside herself, and she did not feel comfortable in revealing it to her family at that moment, or perhaps because of the need to prove that she would be able to overcome the difficulties and complete the task even without the aid of her sight.

In the end, Beatriz managed to type in the body of the email and send it. She said she would have liked to write more content, but had to be succinct due to typing difficulties. Beatriz was proud to have overcome this obstacle and confident in her learning capacity, she did not feel underestimated, neither incapable. The Self Report on the work is presented in Table VI below. It should be noted that the editing of the text was minimal, keeping the expressions of the participant and limiting it to punctuations and accents such as circumflex, crasis, and question marks not located by the participant at the time of typing.

# Table VI: "SELF REPORT" excerpt

[...] But, it was in my second and third course, now already blind that I really found myself, massage therapy makes me enter into an inner peace when I apply it, I think about how the body is so big and at the same time so small, the points that are relieved with a touch, but that can also be easily hurt with a wrong massage. Making my hands travel a path that leads the person receiving the massage to relief and relaxation. I only really got into massage when I started doing the course again with no sight left. At the beginning, it was just one more course for me, as I already had a basic notion of what it was, I decided to do one more, but without the intention of it becoming my profession, after all, I was already receiving a pension. It was merely one more course to occupy my mind, to pass the time. I started to do it and I became interested because I realized that it was much more than what I imagined it could be, it was more intense than when I did it with my eyes open. Now I had another world view and I also identified myself with massage therapy. Being able to help others with therapy, to be of use to someone, even in my current condition, was decisive for me. It is very sad to realise that people see that you have become just someone who needs help and never someone who can help.

There are no words that express the feeling of being able to help others, I don't know if everyone feels the same happiness and values the touch as I do, but I would like everyone to feel the same pleasure in working in what they like, in loving their profession, in recognising it also as a gift. I would rather not stop taking new courses, even knowing that for the handicapped things are more complicated, even so, we can never stop seeking new knowledge.

Source: text by Beatriz.

## Life Line

When Beatriz built her lifeline, we were in the social isolation phase and, besides the original objective, the use of the instrument at that moment also had the intention of reducing the distance between us and keeping her involved with the research. The lifeline is a visual presentation tool which may combine quantitative and qualitative

information by means of an illustration, that is, a graph. Asking the participant to draw the lifeline is the same as asking him/her to make a relationship between past and present in a clear and coherent manner, in chronological order, revealing the importance and significance of each event in his/her history. It is about visually simplifying the communication process by replacing extensive texts with symbols, figures, or keywords (MORIŃA, 2017).

According to Moriña (2017), there are several ways to perform the lifeline, which can be linear without including any type of measurement, can include numbers to quantify as more or less, higher or lower, or even use the valuation of events as negative or positive. Whatever the option chosen, the author stresses that this is a technique that complements or confirms a life history in a simplified manner, although it is used when combined with other instruments, and a semi-structured interview may be necessary to clarify the facts.

Given the singularities of the participant of this study, we discussed the best way to outline the line of her life, considering the lack of vision and difficulties in using the computer. It was established, according to her needs, that she would write a linear text, in chronological order, without quantifications such as major, minor, more, less, positive, negative, that is, without value judgment, but with keywords and year of the event recording only those significant in the course of her life. Beatriz sent a text by e-mail with dates and events which were important to her, and it was clear how quickly she improved when compared to the first time she had written a Self Report, which she was very enthusiastic about. We agreed that the researcher would organize it in an infographic, since it was not feasible for the participant, however, she would accompany the process of building the chart with her text.

After sending it, we talked by video call about the arrangement on the timeline, and she remembered two facts that she had forgotten, but that she would like to have included. When the lifeline was concluded with the data she had sent and in the order in which she had constructed it. I described to Beatriz in detail what it would look like, the type of chart used, and I also read all the content, obtaining her final approval. As a democratic process of intense participation and involvement, Beatriz's word was always valued in the decision-making process during the collection of her narratives, transcriptions and data treatment, as well as in the presentation, arrangement, and writing. It is worth mentioning that the titles of the dates in the lifeline were given by the participant herself and kept by the researcher. In Table VII below follows the text sent, whose concluded lifeline the reader will contemplate in the final text of her life history. There was no need for a semi-structured interview to elaborate on the events mentioned in her text, since they were spontaneously commented on during the in-depth interviews.

#### Table VII: "Life Line" text

2003- Working in the bakery.

2004- Good year, when I started dating.

2005- I started studying English, computing and sugar and alcohol.

2006- I did a massage course.

2007 - I had a serious accident and started a course in food and beverage.

2008- I finished the food course, graduation, what a joy!

2009- Internship in the vineyard I went to the beach.

2010- New job and new plans.

2011- I suffered the assault.

2012- Birth of my niece, a joy in my life.

2012- I found out that I would never see again.

2013- I met the Visually Impaired Association (Associação de Deficientes Visuais - ADVAR).

2014- My abuser got out of jail and went to the mental institution.

2015- I rode my bike alone in the association.

2016- Braille and computer course.

2017- I sold my bike, how sad. I attended a lecture for blind women.

2017- I started a Massage Therapy course.

2017- I did a course in Relaxing Massage and crochet.

2018- My abuser is out of the mental institution, my peace is over!

2018- The aunt who saved my life passed away.

2020- I agreed to participate in the research.

Source: text by Beatriz.

#### Interview with Other Informants

The last instrument used to construct Beatriz's life history was the interview with other informants, conducted after the relaxation of social isolation, however, taking all necessary preventive measures. According to Moriña (2017), this technique consists of semi-structured interviews conducted with people considered key in the trajectory of the protagonist of the life history. This instrument allows the construction of different voices and points of view that dialogue and complement the speech of the protagonist, which results in multiple views of the same reality forming a polyphony of voices (PUJADAS, 2000; MORIÑA, 2017).

The people interviewed were chosen by Beatriz taking into account the importance of each one in the reconstruction of her life history, representing different and essential phases for the understanding of her trajectory. The semi-structured interviews were built together with Beatriz who, inclusive, prepared some questions for each interviewee, which she considered important for the

composition of her history. After deciding on the participants and outlining the questions, Beatriz contacted each of them to extend the invitation. All accepted immediately and then agreed on the best day and format with the researcher.

The first to be interviewed was Wagner, Beatriz's teacher in the Therapeutic Massage and Relaxing Massage courses she took after losing her sight. For Beatriz, this is an essential person in the construction of her history. From a dream of teaching the massage techniques for people with visual impairment and offering the courses, sometimes with his own financial resources, Wagner made Beatriz's current profession possible, adapting all the content to her needs and offering support, clarifying doubts even nowadays when necessary.

The interview with Wagner was conducted in person at the researcher's home and lasted two hours and four minutes. As previously mentioned, the questions were prepared in partnership with Beatriz and covered issues such as his performance in the course, difficulties, potential, and achievements.

The second interviewee was Bela, Beatriz's aunt, for whom she feels much appreciation and gratitude. Beatriz lived with Bela in the period when she suffered the aggression and the aunt was by her side in all difficult moments such as surgeries, trips to São Paulo, recovery, etc. The questions permeated Bela's view of the assault, the moments after it, the changes in Beatriz and her current identity. The interview took place at Bela's home and lasted one hour and thirty-four minutes, during which she became emotional a few times.

Finally, the third interviewee was Ivana, Beatriz's client for two years, who maintains constancy in the services, therefore, chosen to talk about Beatriz as a massage therapist. Ivana suffers from fibromyalgia, and this was the reason that made her resort to massages. The interview lasted eighteen minutes and occurred by video call, and although in a short period of time, it was accurate and with relevant information for the reconstruction of the life story.

The three interviews were transcribed, read several times and the key aspects for the composition of the life story were underlined. In Table VIII below, as an example, we present the script of one of them, prepared by the researcher and Beatriz. It should be emphasised that this is a semi-structured interview, which presupposes that these were only the initial questions, and that some were answered spontaneously by the interviewee, while others emerged during the dialogue. Table VIII below presents one of the interview scripts:

### Table VIII: Interview with Wagner

- 1. How did you meet Beatriz?
- 2. What was your impression of her at the time you met her?
- 3. Could you tell me a bit about the experience of running the Massage Therapy course for people with blindness and low vision?
- 4. Could you describe the student Beatriz?
- 5. Did Beatriz have difficulties during the course?
- 6. If yes, which ones?
- 7. How did you overcome the difficulties?
- 8. Did you notice any potentialities in Beatriz?
- 9. If so, what was the potential?
- 10. Have you noticed any changes in Beatriz during the course?
- 11. If so, what changed?
- 12. Did you imagine that Massage Therapy would become Beatriz' profession? Why?
- 13. How would you describe the professional Beatriz?
- 14. Do you have any information you would like to add?

Source: elaborated by the author together with Beatriz

# 5.

# Narrative Analysis

The choice of how the data of a research will be analysed must correspond to the ideals of each proposed method so that it does not fail to contemplate the intentionality of the study, invalidating the entire methodological path taken and making it impossible to interpret and signify what was collected. From this perspective, the narrative analysis starts from the principle of giving voice and remaining faithful to the perceptions of the very person who narrates life experiences, which corresponds perfectly to the Life History method adopted.

This type of analysis is performed at the same time that the data is being collected concurrently and is favoured when there is a single participant, as in the case of this study, since it is analysed together with the protagonist without the intentionality of creating categories or comparing his story to that of others. The greatest existing concern is to keep as faithful as possible to the life of the narrator reconstructing their trajectory, which involves organising the elements collected so that it becomes a coherent story, clear, permeated with sense and meanings that express authentically the individuality of a life, without manipulating the voice of the one who narrates (MORIÑA, 2017).

In short, the narrative analysis seeks to contemplate the story as a whole, without any fragmentation, thus the importance of collecting and analysing the data simultaneously avoiding that the researcher is faced with a large amount of accumulated information and whose details and meanings have been lost over time. The data when analysed together with the narrator, as already explained in previous topics, allows the information to be organised following a temporal logic, which provides meaning to the reader.

Moriña (2017) explains that people tell the stories of their lives, and the researchers have the role of converting these accounts with the most appropriate methodological treatment to the life history method. According to the author, in narrative analysis the story should be approached considering its uniqueness and the narrative constitutes the central point of the analysis. In this sense, the author lists some steps that are essential to the analysis path, such as reading all the information collected, then organising this information in a chronological order from the past to the present and identifying the key moments narrated by the participant.

Finally, it emphasises the importance of maintaining neutrality at the time of analysis in relation to the narrated story. The researcher is not there to judge, question or prioritise their interpretation of the story itself, but to faithfully give visibility and voice to the narrator. In this way, the moments in which participant and researcher negotiate and together analyse the writing of the text are of great relevance. At the appropriate moment, the researcher will place themself, presenting their subjectivity and interpretation, making it explicit to the reader that at this stage it is the researcher who is speaking.

Moriña explains that he has labelled as the *omnicomprehensive* model the analysis in which the researcher performs different readings for each life history considering them unique, singular, which results in a direction of five looks to the story told, which ensure respect,

trustworthiness, and sensitivity to their particularities, and they are **holistic; focused; thematic; chronological and subjective** (2017, p. 82) to which we adopted and listed below:

#### Holistic Look

The holistic look refers to contemplating the story as a whole, focusing on the individuality and specificities of the person narrating their life. Looking at the whole is possible when the interview recordings are listened to, transcribed and read several times. The process of narrative analysis began already in the transcriptions of the interviews which, in turn, constitutes a decisive moment for the researcher to deepen, get involved and interpret the narrator's account. The transcription was always done the day after the interview so that details such as silence, pause, tears, laughter, uncertainty, hesitation, or others were still present in the memory, since these details may go unnoticed when relying solely on the audio resource. These peculiarities of Beatriz's narrative were explained in the transcriptions in brackets. We used capital letters to designate the altered voice and exclamation marks to identify indignation or surprise.

The transcription process is dense, time-consuming and requires total availability, concentration, as well as physical and emotional stamina. The interviews lasted from two to three hours, which required thirteen to eighteen hours of transcription, totalling around thirty to forty pages of text in each interview. As agreed with the participant, during transcription there was editing going by the orthographic standards of the written language, which implies correcting only mistakes of Portuguese, verbal conjugation, plural,

among others. The intentionality in editing the text was not to propagate stigmas about the participant when it could fail to hear his voice by staying stuck to the spelling rules, barring the fluidity of reading and silencing. The expressions that characterized Beatriz's style were kept, as well as the meaning. Beatriz was aware of all the edits and reviewed all the texts to assess whether they corresponded, in fact, to her way of expressing herself.

In this perspective, immediately after the interview the report was transcribed, edited, and the main aspects listed in a new text that during the next meeting was read to Beatriz so that she could approve, correct, alter or add something. The texts were always read at the beginning of the interview to remind her of the central points of the last conversation and sent by e-mail to the participant, who listened to them slowly and analysed them without the emotion of the moment and the presence of the researcher. During this period, the researcher carried out several readings of the transcribed text, a process that already provided an analysis of what was being raised, as well as the paths followed, what could be deepened, the themes that emerged, what had not been contemplated and consequently, where we would start in the next meeting, that is, a holistic look.

# **Focused Look**

After looking at the whole, it is important to have a focused look, that is, to perceive the details of the reports and this is possible through the data obtained in each instrument used. The instruments previously described in this study were systematically recorded on file, read several times so that the details that emerged and that perhaps would not emerge otherwise, could be apprehended.

The details observed and recorded by the researcher in "A day in the life of..." brought to light elements that might not have been said by the participant such as, for example, her serious and concentrated posture, the need for silence so that she knows her body with her hands, her concern for her patient's wellbeing, how she reacts to unforeseen events such as the massager falling, the ventilator that was not positioned in the desired direction, strategy to check the payment. Although these details may seem small and could be ignored even by Beatriz who deals with them on a daily basis, they may be significant to understand the work environment, complications and overcoming strategies, or the way she presents herself.

In the same way, the "Self Report" brought relevant information which subsequently led to conversations through triggering phrases. The Self Report made it possible to look at a detail contained in a sentence written by Beatriz in which she highlighted the stigma related to disability and which may even guide the professional choice when she refers to the preference for some disabilities considered milder to the detriment of others. The guidance was for her to write about her work and the importance it has in her life, and beyond that, the participant raised the issue of stigma.

A look focused on Beatriz's Life Line highlighted themes that were considered important to her and clearly revealed how she identifies her life by a before and after disability. Beatriz raises on the line details of a busy life within the daily normality of who works, studies, plans and after, how she relearned to celebrate conquests that previously would seem small, such as riding a bicycle. Some issues highlighted in her lifeline had not been raised in the narratives,

however, emerged in the text built in this instrument and would compose the next dialogues in open interviews.

Although the details that emerge from the instruments may seem small, they reveal what makes this story unique and their daily life authentic, rich in experiences, feelings, reactions, confrontation, acceptance of society, of stigma, of their own limitations and disability.

# Thematic Look

So far, we have already had a holistic look where we observed the whole through numerous readings of the transcripts, and also a focused look where we observed and recorded details provided by the instruments. This is the phase of the analysis in which we adopt a thematic look, which implies exploring each transcribed account without a preconceived system of categories. Rather, the themes emerged from the narrative of the participant herself, from what she considered important to be said, from her perceptions about what was necessary to narrate (MORIÑA, 2017). Thus, the information was organised based on the different themes that Beatriz raised and interpreted as significant for the interview.

It is necessary to clarify that the researcher went into the field with a clear understanding of the main theme of the study, namely, the stigma experienced by the person with disabilities, how/if they recognise it and how/if they face it. However, the researcher's topic of interest is not cast upon the participant as if she could or should provide a ready and finished answer. Rather, the participant speaks freely about the themes of their interest and choice, to which they judge important and significant and based on the information kindly

granted, the researcher was able to contemplate traces, indications, and evidence of what she sought to investigate. In this phase, the subjectivity of the researcher comes into play, in addition to that placed by the participant, when she interprets as stigma the situations narrated under other themes raised autonomously by Beatriz. When looking at something said on the perception of the other, it is possible to contemplate a new angle, but this will be detailed further on.

Given the above, we adopted some steps to organize all the information under a thematic look. The first of these was again the reading of the whole. The transcribed text was read at length with maximum attention to identify each theme raised by the participant in her narrative. In a further reading, the themes already clear to the researcher were noted down, totalling 13: Identity; Family; Friendships; Relationships; Training; Work; Plans; Fears; Faith; Assault; Aggression; Aggressor; Disability; Society. It is noteworthy that the thirteen themes explained were raised through the first four interviews until the moment of social isolation, i.e., they were built until personal contact was interrupted. After five months of interruption of face-to-face interviews, we returned and conducted two more interviews, and the theme Stigma emerged.

The third step followed the annotations of the themes that emerged through the new reading, and consisted in separating each theme from its original text by placing it in a table with a title. In this way, all the statements related to Beatriz's personality, likes, aptitudes and personal characteristics were grouped together in a table entitled "Identity". Following this, all the things said about her parents, sisters, aunts, and others with kinship covering relationships, affinities, misunderstandings, and feelings were grouped together in the table entitled "Family". In the same way, the narratives about

friends from the time when she could see, as well as those she met after losing sight, were placed in the table entitled "Friendships". Following on, the love relationships experienced before and after the assault suffered were grouped in the table "Relationships". Everything that refers to school life and professional courses are in the "Education" table. In the "Work" table, we grouped the statements on the functions performed before the disability and the interaction that took place, the choice of the new profession in the second phase of her life and her experiences. From this perspective, the information on the plans she had up to the moment she was assaulted and the plans she has made up to the present moment have been placed in the table "Plans". The narratives about what causes her fear were systematized in the table "Fears", as well as reports about spirituality that served as a basis to compose the table "Faith".

The most difficult reports about the day she was assaulted, as well as the days of the first year after the assault, were selected for the table "The Assault". It is emphasised here that the choice for grouping the day of the assault with those that followed it and not separately in a specific table for the moments after the assault, justified by the fact that they are intensely interlinked for Beatriz, as if the days after, extension of the day of the assault, were one and the same day, one and the same nightmare, a succession of pains and slow and painful discoveries for her. The day of the assault and the first year after, are for Beatriz like a single day and only after the first year did she deconstruct the old identity and accept the new one that presented itself. This was perceived during the interview, listening to the audio and careful reading of the transcription in which Beatriz talks about the first year with the same pain, intensity and vehemence, not distinguishing the temporal separation, not differentiating the time

elapsed. An intense effort was necessary on the part of the researcher to understand what happened on the day she was assaulted (surgeries, circumstances, other people's demeanour) and what happened months later. Even having clarified, in respect to Beatriz's perception, it is that the decision of a single picture, a single pain was made:

It was a year in which I had a lot on my mind. The first year for me, I had all that hope of seeing again, I stayed one year wanting to see. My friends would come and show me some picture and say "I'll save it for you to see later", pictures, reports... so I lived with that expectation, without knowing how it would be (Beatriz).

Immediately afterwards the separations were made about who is the man who assaulted her, the kinship and friendship he had and the experiences and supposed motives, and also her current situation in a table called "The Aggressor".

The table "Disability" includes narratives about the specificities of blindness, difficulties, limitations, discoveries, new ways of being and being in the world. At that moment, there was the separation of what referred to her identity as who she is, what she likes and does (already grouped in the table "Identity") from what was related to disability itself and its consequences. Although they seem similar and inseparable in the participant's own narrative, we understand them as distinct accounts, i.e., beyond the disability, we previously looked at the person. Finally, we separated the narratives on how she is seen, labelled and judged by people outside her family contact, on accessibility barriers and others, allocating them in the table "Society".

Once again we emphasise that these were the themes that emerged from Beatriz, in the period before the social isolation, during the four interviews carried out and in each of them it was possible to contemplate the presence of stigma, even if not said explicitly. Finally, the new interviews carried out during the relaxation of social isolation also went through the same treatment as the initial ones and the table "Stigma" was added, in which Beatriz discussed situations experienced in which she felt stigmatised for her condition as a person with disability.

After the third step, which required a longer look, we proceeded to the fourth step, which consisted of reading each table considering whether the selected texts corresponded to the entitled themes. At this stage, it was possible to realise that the same excerpt could correspond to more than one theme, requiring a decision on which would be prioritised or in other cases, in fact, would remain in more than one frame, as in the example:

In my perspective, Paola cannot understand that I cannot see anymore, that I am handicapped nowadays. She does not want to accept, she thinks I am... I am the 'me' from before. But I am not that person from before, today I have limitations (BEATRIZ).

The excerpt above was placed in the "Identity" table for reflecting on who is the person of today and who was the previous person. It was also grouped in the table "Family" because it deals with the conflicting relationship with the sister. The same excerpt was grouped in the table "Disability" when it specifically narrates consequent limitations.

Up until that moment, the data reflected absolute chaos, and it seemed to make no sense to fragment the texts in this way. However, following the fifth step, which was a new reading of all the tables with a look at the whole and no longer at small fragmented excerpts, it was possible to contemplate the meaning and the new text that was being established, reinvigorating the spirit to continue. In this way, it was possible to understand the importance of valuing the gaze for the whole, even when experiencing chaos.

It is noteworthy that in this phase we were living a historical moment of a world pandemic and social relations interrupted when everyone was kept in isolation for safety, however, Beatriz's participation in the data analysis was necessary, and we did it through conversations on video calls and recorded audio. Beatriz was aware of what the thematic look was about, the themes she raised, and the information contained in each of them, agreeing with the arrangement and organisation, recognising them as legitimate.

The feeling of absolute chaos experienced by the researcher was also experienced by Beatriz in the beginning, before the look at the whole, who showed interest in understanding each theme and still surprised with the amount of information she built. The process that at first seemed difficult for her, stating that she would be unable to build it if she were alone, in the end, was seen as rewarding and interesting.

In this phase, Beatriz raised several questions of doubts that arose, among them, how her lines were placed in such a way that they could remain faithful even to her pauses, laughter, hesitations, and expressions. The question was clarified with the explanation that at the time of transcription, always immediate to the interviews, these particularities present in oral language were still present in the

memory which made possible the registers by means of brackets such as (laughter); (... hesitation); (silence). In fact, this question was an important feedback for the researcher when the participant recognised herself in the transcriptions and texts of the themes. Beatriz also explained which passages she would not like to be published in the thesis, which were selected with strong colours to highlight them. She also made it clear which table she would rather not have published in the thesis in order to preserve her identity and intimate life, a wish that was also respected, which leads to the disregarding of the theme "Relationships" in the writing of her life history, that is, although this table will remain in the data analysis file and all subsequent conversations on the theme will continue to be grouped in it, this information will not be published.

She questioned what the researcher would show in presentations of the thesis at events and boards of examiners. At this point, the topic of stigma arose, which although mentioned in the reading of the informed consent form, was forgotten by the participant. The researcher explained how a presentation is made, going through an introduction of the investigated theme, the objective and method, the life story and the final considerations about the whole. Beatriz wanted to know about the meaning of stigma which was explained to her and showed interest in reflecting on situations in which she was stigmatized, already narrated to the researcher, but without being aware of what they actually meant in society.

This issue triggered curiosity about other ways of doing research, asking if it is possible in a single interview to obtain as much information as we have constructed. The researcher described that this is the main characteristic of the method we carry out, that is, the

depth and closeness that cannot be built in quick interviews or in a single day. As feedback, she narrated about the empathy she felt since the first interview, claiming that the trust, identification, and proximity were crucial for her to speak comfortably and in a free, detailed and spontaneous way about her life, which did not occur in other interviews that she has already granted to broadcasters that sought her due to the great repercussion and commotion that the aggression suffered caused.

In view of the above, a synthesis of Beatriz's participation at the time of the thematic analysis is valid:

#### Table IX: Participation in the analysis.

**Thematic look:** She initially considered it a dense and difficult process, but then understood it and found it interesting.

**Presentation of the thesis:** She asks about what will be said in presentations of the thesis at events and boards. She takes an interest and raises questions.

**Stigma:** She asks about what stigma is, becomes interested, understands and reflects on situations she has previously described to the researcher in which she was stigmatised, but without knowing what it meant.

**Particularities of the method:** She asks about the method and is intrigued to learn about how information is gathered in other types of collection, she is fascinated by the specificities of the life history method.

**Feedback:** She recounts her experience with the interviews, the closeness, and trust she felt with the researcher, about other interviews granted in which she did not fully open up about her life, how comfortable and secure she feels to tell details of her life and participate in the study.

**Themes:** She listens attentively to the reading about each theme and excerpts that represent it, talks to the researcher about them, agrees with the organization and is satisfied with the look on the whole. Beatriz asks how the researcher managed to portray her expressions and moments in which she smiled or emphasised some explanation. She made remarks about passages and pictures that she would not like to expose in the thesis.

Source: Elaborated by the author.

The *online* conversations about the research during the pandemic and the social distance made it possible for us to remain close, preserving the bond we had built and also maintained Beatriz's growing interest in the research, in the impact it would have on society, in the reflections it would raise on disability and stigma. Being informed and participating in the analysis process was very relevant for her to fully experience the meaning of a method in which the roles are shared. Beatriz even mastered the terms used in academic language, acquiring knowledge about the method in which she participates and reading articles on the theme of disability and work.

In the Life History method, the researcher puts herself in the place of the participant, and the participant in the place of the researcher, deconstructing hierarchies, building knowledge, empathy, that is, the ability to see the world through the other's view. The researcher learns from the participant about stigma in practice, about coping, about experiences different from her own. The participant learns from the researcher about stigma in theory, about method, analysis, and about signifying her own experiences from another perspective. Both learn about the importance of each one in the construction of a life history.

## **Chronological Look**

After the thematic look in which all information, without exceptions, was grouped in tables with the corresponding themes forming new texts, the next step was to organize this information in a temporal sequence. It is known that in oral language, even if there is intentionality, narratives do not follow a rigid logic of chronological order, i.e., while narrating the present, there are mentions to the past

or future, which does not produce a discourse in evolutionary sequence.

There was a concern to respect the temporal style of the participant herself, who narrates her history explicitly marked in three times: life before the assault; life in the first year in which she suffered the assault and life after the first year of the assault until today. Following the same line, in the phase of the chronological look, we built three new tables to (re) group the information already separated by themes. The first table was entitled "First Stage: the Normalcy" and in it were grouped all the thematic information that happened when Beatriz was living life within what we know as normality. We continued respecting the thematic order, which implies keeping the titles with their respective texts, however, within a new time frame.

In the same way it happened with the second picture entitled "Second Stage: the Assault" in which we kept the information with the corresponding titles (family, faith, fears, assault, etc.), but in a new picture corresponding to the time in which they occurred, (the day of the assault to the first year after) for the reasons explained in the previous topic in which the addition of the day of the assault to the first year after is justified. In the sequence, all the themes raised during the third stage of Beatriz's life were grouped in the table entitled "Third Stage: the Disability" which refers to the facts that occurred since the days that passed after the first year of the aggression when she was discovered as a person with disability until the moment of the construction of her life history.

Organising the narratives that were already thematically separated was a process that, although not as exhaustive as the thematic look, demanded attention and time, since it was easy to get lost in the data when transferring and reorganising them. As a

strategy, in each excerpt selected the theme and time to which they referred were repeated out loud, for example "Family Theme, Third Time". It was necessary to create strategies like this, to maintain concentration and activate the memory when, after the tenth page, the process to find the place where the text would be inserted took a long time, which consequently could result in a mistake as to the time or forgetting the theme. It was still possible to refine small passages that, at this stage, seemed to clearly belong to another theme, but that had gone unnoticed before.

Similarly to the phase of the thematic look, a new chaos seemed to impose itself with the narratives, as well as new fragmentations in a single paragraph or sentence to obey the chronological logic seemed to make no sense or have a reason. However, in the end, through a new look at the overall picture, it was possible to see how this organization provided more focus on what really needed to be contemplated in the life story, making it easier to reconstruct it. Several pieces of information that were "inserted" in the same sentence or paragraph when separated in chronological tables could be easily excluded, when unnecessary for the composition of the story, considering the limited number of pages (although there is no strict or explicit rule, the desirable is that the story occupies approximately forty pages), a fact that allowed a focused look and a clear and continuous text without deviating from the interest and objective of the study.

Finally, in a last reading of the chronological tables, a new organisation was carried out within each stage, that is, the information that was only grouped within the three stages without the concern in leaving them in the order of events (but only if they occurred in the first, second, or third stage), was in this phase

organised in detail in a faithful sequence from childhood to the present day. Finally, aspects considered fundamental and key passages for the composition and presentation of the life history in the final text presented to the readers were highlighted from the text together with Beatriz.

#### **Subjective Look**

According to Moriña (2017), subjectivity is understood from a dual perspective that involves the protagonist of the life story, i.e., the one who narrates his life and also the researcher. To imprint and value the subjectivity of the participant, it is necessary to offer the necessary conditions for them to participate in the entire process, from when they agree to narrate their story to the organisation and analysis of data. Beatriz saw herself reflected in the story constructed, made sure that the researcher was faithful to her words and experiences, as well as her pain and emotions, had the last word in decision-making, reviewed each text about her story, as well as each theme that emerged deciding which would be contemplated, approved, completed and analysed everything that was being built. She took possession of the knowledge about stigma, and re-signified her own experiences, and at the end of this whole process she guaranteed and recognised her subjectivity in the study.

On the other hand, for Moriña (2017) it is inevitable not to also print the subjectivity of the researcher, since it is them who carry out the transcriptions and edits that subsequently organised constitute the life story for the reader, who triggers by means of a sentence the dialogue that follows, listens, dialogues and interprets what is being said to them and beyond, their subjective look is placed

when they manifest their interpretation of the story in the analysis that until then remained within themself.

It is necessary to point out that through the five looks described, Beatriz's voice was present in a remarkable way, it was respected and valued, and the researcher had the role of being as neutral as possible so that the participant's protagonism would stand out. However, at the end of the process there is a conclusion, and this, from another perspective, presupposes a re-reading and interpretation from the perspective and perceptions of those who heard and lived through the whole process, in other words, the conclusions from the researcher's perspective, which will be explicit in the title that, at this moment, she is the one speaking. At the end of numerous readings from the time of the interviews, preparation of summaries for reading with the participant, transcriptions and narrative analysis through the five looks, the researcher found herself deeply involved with the data, to the point of knowing them in every comma, exclamation, laughter, tears, or silence.

From this perspective, the next chapter shows the life history, narrated in the first person in which Beatriz's voice stands out through a neutral text, i.e. the participant's narrative will not be interrupted with the researchers' comments, before, the text will be continuous as well as the interviews. The intentionality at that time when the neutrality of the researchers was maintained as it occurred during the interviews through a listening that Augras (2009) calls respectful, was that Beatriz's voice could be heard without interference from other voices, whether dominant, political, academic or even from the researchers themselves.

In the chapter "The Life History" the reader finds Beatriz's voice narrating the remarkable moments in her history that have

made her the person she is today. Beatriz explains, in the first person, her perceptions about everything that happened to her, about disability, society, and stigma. She also talks about attitudes, confrontation, and feelings. The reader will be able to identify the tools explained here in the construction of the history, which help in the final composition of the story. In some moments, there will appear voices of family and friends who will talk about Beatriz herself, but they are understood as complementary and not as protagonists, which are highlighted by indentation and smaller font size so that the reader may immediately differentiate them. The "life line", "Self report" and the dialogue that emerged from the instrument "A Day in the Life Of..." will also be marked in brackets for identification.

The presentation of Beatriz's life history in this paper will not be intended as a discussion on disability, but as an exclusively didactic purpose on possibilities on the path of building life histories.

# 6. Beatriz' Life History

## Normalcy

My name is Beatriz, I am 37 years old, a massage therapist and married to Elis. Until I was twenty-eight, I lived a normal life, like any person my age. My childhood was peaceful, my mother worked as a maid and my father in a sugar and alcohol producing mill. I am the eldest daughter and I have two sisters, Paola, the middle daughter and Juliana, ten years younger. I was always a quiet, docile child, I did not quarrel with anyone, I never did anything naughty and when I got beaten it was because my sister Paola did something wrong. I had responsibilities from an early age. When Juliana was born, I washed and ironed her clothes while my mother was in hospital. When my mother went back to work, I was the one taking care of the baby, which made me sad sometimes because I wanted to be able to play like her middle sister.

One thing I find strange was my preference for a game I invented. I used to pretend to be blind! I remember clearly that with the handle of the squeegee I walked from my mother's room, with my eyes closed, tapping it as I walked to guide myself, I passed through my room, the kitchen, the living room, guiding myself with the invented cane, groping and imagining what it was like to be blind. I did not have contact with any blind person, but I used to play this game and imagine how it would be to be in this condition. When

Juliana was born, my mother took us to a 'benzedeira' who was blind. She had two white eyes and I thought she could see. I remember that we sat close to her and I would not go near her, I was afraid, I would watch her face and doubt that she was really blind. I would look at her white eyes and think, "this woman can see me". I think people think this about me too, that maybe I can see them.

One day, when I arrived at this woman's house, I noticed that she was cutting up chicken and cooking. Then I was sure that the woman could see. Everything frightened me about that woman, her expressions, her mannerisms, her white eyes and even her hands with the marks of time, thin and dry skin. This was my only contact with a blind person, although I was already playing and imagining that I was blind long before I met this lady.

I can't explain why, this is something I don't understand, but I simply grabbed a stick, turned it into my cane and walked around the house with my eyes closed, imagining that I was blind, feeling blind. God knows all the things in our lives, He knows everything we are going to go through, and maybe He was preparing me. Why would a child play like that? I hadn't lived with a person in such a situation, I wouldn't have had any reason to want to play like that.

# My place...

In my teenage years I became even more coy and shy, I didn't talk to anyone, I kept to myself. I felt very ashamed, I was always very quiet at school, I always hung out with the same people in class breaks, sitting around, talking to a few of my closest friends. I only went out to go to church, sometimes I had an ice cream, but by ten o'clock at night I had to be home. My teen years were not one of

dating. I was quite easygoing and felt embarrassed about everything. I was always the one that didn't say much.

I was a diligent student as a teenager, I was part of groups that contributed to the school, and I dreamed of becoming a psychologist. I remember I had a book with the title "Psychology", it didn't even have a cover, it talked about the mind and that interested me, it caught my attention. I liked to read and write in diaries, but I was always very introspective. My family would invite my sister for walks, but they wouldn't call me because I didn't like to talk, to chat, and so they wouldn't bring me along.

When I was about to turn eighteen, I went to live with my aunts, who had their house in the same yard. There were three single uncles who lived in the house next door. My uncle passed away, and I started sleeping there, keeping my aunts company. I started going to my parents' house only at night, as a guest. I was always with my aunts in an environment that was the opposite of my parents' house. It was a calm, tranquil environment, a real refuge. Because I was so young, living with older people, that changed me a lot and changed me positively.

Beatriz was a girl who listened to us a lot, she was very obedient and listened to me and to Carina, my sister, who passed away. Carina always taught her to put away her clothes properly, to take off her shoes and put them away, so she grew up being organised. You can notice that in her house everything is well-organised, considering the current situation. If it were someone else, they would leave everything disorganised, but not her, she does everything well. She learned everything here from us. So, we got a lot of love from

living so close together! Then she grew up, studied, went to work (Bela, Beatriz's aunt).

With my elderly aunts, among other things, I learned empathy. For instance, from them, I learned to respect others in the smallest things, like how to be careful not to make noise when arriving home when they were already asleep. When I was living with them, I went out a lot because I was young, but I always took my shoes off right at the door, entered carefully, went to the bathroom with the light off because they were asleep. I took this care, as did many others, but at my parents' and sisters' house it was the opposite of what it was at my aunts' house. There was noise, impatience from everyone, nervous people, swearing, so I didn't adapt to that anymore.

I changed and perfected myself in my aunts' home, which became my own home and in which I even got a room where I kept all the things most precious to me, like my collection of soaps, my guitar called Ariel, the diaries with my notes, my moon-shaped bear hanging from the lamp, the stars placed on the ceiling.

At that time in my life, it was just the three of us, my two aunts and me. My parents and sisters were next door and if when I visited them and for some reason witnessed some argument, I would simply leave for my aunts' house, I would no longer stay where I did not fit in because now I had somewhere to go back to, I had found my place, my peace, the refuge I had sought for so much in my childhood, my silence, however, even that was abruptly snatched away from me...

#### A new phase in my life...

I became increasingly more communicative and more social when I started to work in a bakery, where I stayed for seven years and interacted with a variety of people. I started as a clerk and in a short time I was showing signs of my development, I was already becoming more communicative, I was talking to the owner, work colleagues and customers.

Despite my shyness, I loved to work, I interacted well with everyone and I had a special affection for the elderly who used to shop in the bakery. I felt sorry for them because they didn't have someone to help them and I worried about how they would get back home, what obstacles they would encounter on the way back, I was already worried about the issue of accessibility.

Even today, there are people who come to me to say that I always treated them very well and complain about the current service. As I would always treat customers with kindness, I can't imagine anyone mistreating them, they are elderly, innocent people, I couldn't bear to witness any rudeness towards these people. I remember that the elderly, in their innocence and trust, would buy the products and put their little money so that I would check and get the correct amount. Sometimes, when they had difficulties going down the steps of the bakery, I would leave the counter to help them or even accompany them to their homes. Today, with my limitations, I see how many people have helped me and continue to help me, so I think I am reaping what I planted back then. I did everything out of love, without interest, but today I receive that love in return.

I was a clerk, cleaner, attendant, pizza maker and baker without earning anything extra for extra services. I never earned a cent

more, I never earned to work on holidays, absolutely nothing! The bosses were always very good to me in other aspects, but I was not paid for the extra hours, I had no time for personal life, I had no life outside the work environment. I worked from Monday to Saturday and even on Sundays. As I was the one making the bread, I had to go in before the other employees. When the others arrived, I was already baking the bread. They were exhausting hours, when I left work I didn't feel like going out with friends because I was so tired, but even so it was the best time I ever lived, from the age of twenty until I was twenty-seven, without a doubt it was the best phase, I spent most of my time there, I ate there, in short... I learned a lot, I grew, I matured, I suffered, I cried, but I also had joys, I made friends, some of them true, others not so much, I learned to deal with customers, with people of all kinds...

As everything in our lives is a cycle, my time at the bakery ended, I joined a beverage factory, and it was a totally different environment from what I was used to. I started to get a taste for what I had never experienced before, like more spare time to take care of and invest in myself, go out and connect with other people.

Beatriz was very dedicated and hard-working, if you lend her a penny, even if you forget and don't even want it back, she makes a point of paying you back, she is a very honest and punctual girl. Then she started working at the beverage factory, she'd get up very early in the morning, so I never let her leave without breakfast, ever! She would have breakfast and tell me 'Bye, Bela', and I would reply 'Bye, Beatriz! Go with God, may God be with you' and she would leave on her little motorbike. (Bela, Beatriz's aunt).

## Many plans and the end of a cycle...

During this time I worked in the beverage factory, the desire to study was awakened in me. I studied to be a masseuse and took a course in Lymphatic Massage, falling in love with that field. I read many books and researched the subject which became everything in my life.

I was totally dependent on my sight and did little exercise on the other senses. However, the advantage was that with sight I could search the books as many times as necessary, and it was much easier to clear up any questions. Today everything is much more difficult in that sense, but back then I couldn't feel every part of the human body as much as I do now.

I wanted to continue taking massage courses, I wanted to take a course where I would learn to walk with my feet on the person's back, unfortunately this course didn't get enough people signed up to open a class. But the real reason that made me leave massage was shyness. I was too embarrassed to touch anyone. As soon as I finished the course, many people wanted me to give them massages, including Nívea, a masseuse who was like a mother to me and the person who most encouraged me to take the course, she was the one who gave me my first stretcher.

However, I left the idea of working as a masseuse aside and continued working hard in the factory. I am a person who prioritises and values work, I have to work, I think about making money. I've always been like that, and during the time I was in the factory, I also had another job as a nanny at night. I endured the double shift because I loved the money I received at the beginning of the month. For me, the beverage factory was a place that matured me, I learnt to

value myself in relation to money, education, I learnt to drive, I planned to go to college. I chose to study for a degree in environment and I had already filled out the papers, everything was already right for me to start college. I worked during the day at the factory, at night as a nanny, and I was dating, with plans for a marital union. It was a busy life, I didn't have much time, so I opted for distance learning.

I admire everything about Beatriz! I admire everything! Since she was born, I always admired her, and she was growing up and becoming an educated girl, diligent in everything she does, she went to church with us, a confident girl, wise, she started working early taking care of children and was not a girl to spend her money on nonsense. Today, I admire her much more for overcoming so much in face of all that she went through. But, I always admired her for everything, her good memory, her dreams, her strength, the fact that she wanted to go to college, the courses she took to become a masseuse (Bela, Beatriz's aunt).

Many plans, a busy life and endless possibilities presenting themselves in front of me. In September 2011, the factory gave me time off, although I didn't want any, I liked my active life. I protested, but I thought it might be good to have a little time to rest and visit friends, as soon my life would become even more busy with college and marriage. What I didn't know, however, was how much my life would change forever during that time off and that things would never be the same again.

I left the beverage factory not knowing that I wouldn't be back. On the way out I passed a walker who always stopped to talk to me, we smiled and talked. I stared at his face without knowing that it

would be the last time I would see him. He wished that God would accompany me, and I left riding my motorbike with the conviction that I would soon be back. Today, I can say that God really accompanied me when I left that factory, protecting what is most valuable to me... life!

#### **Assault**

It was September 2011. Until the day of the assault, I was full of plans. It's true that I didn't want any time off that month, I told a co-worker that I would rather have it in October, but nothing could be done about it. If I hadn't been on leave, the tragedy that marked the history of my life might have been avoided because I wouldn't have been at home, I would have been working.

On the day it all happened, I was going to visit a friend who gave birth to a baby. As I would soon be going back to work and would not have time to visit her, we agreed that I would go to her house that day. She replied that she would bake a cake to wait for me. However, that day I didn't feel like going out. I keep thinking that if I hadn't been on leave against my will... and if I wasn't preparing to visit a friend, even against my intuition... and if I didn't take a shower at that moment... if my aunt didn't have to use the bathroom next door because I was using ours... I wouldn't have been alone and vulnerable... if... if...

But before telling what happened, let me tell you who my aggressor was. I apologise for not being able to pronounce that man's name, it is too painful and frightening for me, especially because it was someone from my family, in whom I had total trust, who grew up with me, with whom, sitting on the back of his bicycle, I rode

around town without any worry or fear, someone who even lived in my house, my own cousin!

## An ordinary day...

It was a day like any other, everything seemed perfectly ordinary, except for the intuition that persistently told me not to go out that afternoon, not to be alone.

I woke up very early, cleaned the whole house, went to the supermarket and brought home some bread. I went into my social networks, talked to a friend and told her that I would visit someone else, even if I didn't want to. This friend advised me not to go, but I said goodbye and ignored her advice because soon, as I mentioned, I would go back to work and I wouldn't have another opportunity, things would be much rushed for me. The three of us were there, my aunt, my father and me. My father was resting in his house, right next door, my aunt Carina and I were alone in our house.

As I was getting ready to take a shower, I remembered that my cousin had said he would visit us that afternoon, he always called to let me know when he intended to visit us. My cousin suffers from schizophrenia, we were very good friends, I always treated him with respect and consideration, I never treated him with indifference or discrimination as other people used to do. He was always at my house, we talked, I helped him when he needed something, my feeling for him was always of friendship, I treated him as if he were a brother. However, my cousin stopped using the medication for schizophrenia and this worried me, he sometimes got aggressive with other people, but never towards me.

That day I didn't see him around the house before I went into the shower, I have no recollection of it, but I took my clothes with me to the bathroom, just in case, I usually left wrapped in my towel to get dressed in my room. I knew my cousin was there, but I don't remember seeing him, I can't tell if I spoke to him... I don't have that memory. I don't remember passing him by the room, or talking, saying hello, or even catching a glimpse of him. I DON'T REMEMBER seeing, bumping into, or talking to him. But I do remember the announcement of his presence that afternoon...

When I came out of the shower, already dressed and with my hair wrapped in a towel, I saw my aunt Carina opening the little gate that separated the two houses and going towards my father's house. I remember seeing her head covered with white hair, walking away from me. My aunt was going to my parents' house to use the bathroom, since I was occupying the one in our house. I thought of calling her, but I just watched her walk away, thinking to myself "Preta is going to my father's house"...

At that moment, I was alone in the house, at least it seemed that way, although my aunt and father were close by, just next door. I didn't see him in my house... maybe, because of the towel that covered part of my face. I took a step up the stairs that go to the living room and I just heard a loud noise... it was the first blow I had received on my head. Startled, I looked back and saw my cousin with an upset face, with a look of hatred on top of me. I let out only a sigh of terror and surprise without understanding why he had hit me with a hammer, I tried to run, but I could only take two steps forward.

He pulled me by the towel wrapped around my hair and knocked me to the floor. I fell sideways, into my bedroom doorway, and he sat on my waist, immobilizing me. My body laid on its side facing the door with him on top of me, and he started hammering the side of my face at the height of my ear. I asked him to stop, I asked him why he was doing that to me.

He would answer "you killed my puppy", to which I would defend myself "no, I did not kill your puppy", I repeated it over and over again that I had not killed his puppy, by the way, a puppy that did not even exist, but nothing could stop him. The only thing I could do was to grab his neck with my hand, but he moved his head back, and I couldn't reach him anymore. I screamed loudly with all my strength, "Stop! Help! Preta... Father... help!" My aunt and father, although so close, did not hear my cries for help. Maybe if I was in the kitchen they would have been more likely to hear me, but in the room a little far away, it was difficult. I called out a lot for my father and aunt, but they could not hear. I screamed and no one listened.

Totally immobilised, I could only reach the door with my eyes and the only hope at that moment, the only way out I could think of was for someone to enter through that door, that was all I could think of, someone... someone... anyone who could enter and stop the blows to my face...

I was lying in the living room, and he hit me a lot on the right side of my face until I couldn't take it anymore and passed out. When I passed out, he dragged me to the door of my aunt's room. He continued hitting my face with the hammer, he took out my eye, nose, all the skin, broke my jaw, broke my face in half. My aunt arrived at that moment. She was slow to return because she was old, her steps were slow and any activity, however simple, was more difficult and time-consuming for her. However, even with short, slow steps and numerous difficulties in getting around, her steps and voice

were strong enough to stop the aggressor. For me, aunt Carina, whom I affectionately called "Preta" was a saving angel, to whom I owe my life.

When my aunt arrived and saw him crouching down, she imagined that he was attacking the dog. She came in a little further and spotted my legs and shouted at him, who immediately got up. She came closer and tried to turn me over, I was already choking on my own blood. My aunt didn't have the strength to turn me over, so she went back, slowly because she had no agility, and called my father.

My father was faced with the aggressor standing in the doorway, his clothes soiled with blood. Not knowing what exactly had happened, my father just exclaimed, "Just leave. Otherwise, I will kill you!" He opened the gate and left. When my father entered the house, he found my face completely open. Until that moment, my father had thought that he had hit me, but he could not imagine the gravity of the situation, he could not imagine that he had done all that. My father said that the scene he witnessed was simply horrifying. Amidst the blood splattered all over the room, walls, curtains, carpet, he identified my nose bone on the floor and kept it in his pocket, my face was split in half and without the skin that covered it. My father managed to turn me around and stayed with me while my aunt went to call an ambulance. I could hear him talking, upset, "Oh my God, he killed my daughter!" The way they saw me... my father thought I was dead.

My brother then... such a cruelty... he went to the hospital with a little piece of a bone from Beatriz's face kept in his pocket, he didn't know where that piece of bone came from. At the hospital he would hold that little piece of bone and

cry... he would say in tears to a friend who was a nurse working at the hospital "look at my daughter's bone here in my hand" (Bela, Beatriz's aunt).

My struggle for life did not end with the arrival of the ambulance. When I arrived at the hospital, I was lying on a stretcher, with a sheet over my face because nobody had the courage to attend to me. I was losing all my blood because no doctor wanted to help me. The doctors lifted the sheet that covered me, looked at my condition and covered me again. The nurses could not even look at me, nobody wanted to attend to me because my face was destroyed.

Doctor Ruy was not working that day, he had only gone there to discharge a patient. When he arrived and came across my case, he decided that he would operate on me, even though he was not working. He and a nurse who always accompanied him took my trolley and went up to the surgical floor. When they got there, the nurses on that floor barred the door and said that I would not be allowed in, that I was not a responsibility of that hospital. The doctor pushed the trolley against the door that opened and said, "She will be operated right here, get her some blood immediately!".

There wasn't a single bone left untouched in her face. Beatriz lost one eye and has haemorrhaging from the other. (Deputy who took charge of the case, excerpt from an interview with the local news).

My heart rate was already reaching zero, I was losing a lot of blood and I needed to replace it urgently. The first surgery lasted approximately sixteen hours. It was many hours of surgery, with only this one doctor who took responsibility and his auxiliary nurse. The others didn't do anything. They didn't help in any way. Dr. Ruy was an angel in my life, just like my aunt who, if she hadn't interrupted the assault... a few more minutes and I wouldn't have survived. I had this surgery and four days later I woke up from the coma, I did not remember what had happened, I did not know what I was doing there, I did not even imagine that I could not see anymore, I did not have the dimension that my life had changed forever!

## Why me? Thank God it was me!

Beatriz presents the following picture, according to the communications office of Health: Facial mutilation, sinking of the frontal bone, nasoethmoidal fracture, partial tearing of the nose with total loss of the proper bones of the nose and annexes, fracture of the palatine process of the maxilla, bone loss of the upper jaws, fracture of the orbit in bilateral Blowout, laceration and loss of substance of the frontal region, laceration of the upper eyelids, laceration of the upper lip and severe ocular trauma. At the moment she is stable, conscious, calm, tracheostomised, on spontaneous ventilation (Excerpt taken from local newspaper report).

It is so weird, I think it is God because I was not terrified. I had so many people in my hospital room, so many visitors and I still smiled at them all, consoled them with gestures, signalled that I was fine! People joked with me and as I could not speak because I had a tracheotomy, I took their hands, I wanted to show them that I was all right, I had no idea of the seriousness of what had happened to me.

I received visitors at all times, even in an ICU, I cannot explain how those people managed, but they entered my room all the time to visit me. They were people who worked in the hospital and wanted to talk to me, friends, relatives, and others I didn't even know, curious, since my story had great repercussion. They came and introduced themselves and I treated them well, I had no notion of what had happened to me, I did not remember, I could not reason, I do not know how to explain those confusing days.

The nurses brushed my teeth and when I ran my tongue over them, I felt something strange... I worried, I planned to go to the dentist as soon as I got out of that hospital. That was my biggest worry at that moment, I thought there was something wrong with my teeth, when in fact, my whole jaw was collapsed. My entire face was stitched up from the inside. My nose was lying on the stretcher when Doctor Ruy simply picked it up and placed it on my face. The only eyebrow that I have today is actually hair that was implanted, everything was torn off, I didn't even have any facial skin. He took what was left over from the top of my forehead, stretched it and sewed it underneath. But I was worried about going to the dentist without the ability to measure the size of the changes to my disfigured face.

I didn't touch my face, I always kept my hands down for fear of touching myself. I was always very prickly, my head was covered with stitches because my whole face was reconstructed. I was taking stitches from my head, poking but not touching my face. One day, I plucked up the courage and, with great sacrifice, I touched my eyebrow area, very delicately, my fear was not that it would hurt, my fear was that I would know how I was. When I touched the left side of my face, I asked dumbfounded, "where is my eyebrow?" My aunt answered: "Beatriz, you don't have any eyebrows on that side". I

continued: "But it's going to grow, isn't it?" "No, no more eyebrows will grow there, you'll only have one". At that moment, my world fell apart. I cried so much because of that eyebrow until I found out that I wouldn't even have an eye, then the eyebrow became of less importance.

One day, when she could get up from her hospital bed, I took her for a bath. As we walked to the bathroom, she asked, "Bela, will I go blind?" Gee, when she asked me that question, you have no idea...(voice cracking)... what could I possibly say to her? (crying) I said, "You probably will!" I couldn't hide it, could I? I said, "Oh Beatriz, you will probably go blind" and she started to cry. She started to cry and so did I. I took her to bed, the bed was full of tears. I took her to bed, both of us without talking, just crying (Bela, Beatriz's aunt).

Gradually I remembered what had happened and became aware of why I had been in hospital for so long. It took me several days to remember everything that happened and tell my family. Four days after the coma I woke up, but I still did not remember, I went to São Paulo, I had another surgery, the only things I wrote to my family were for them to take care of my aunt, only this, I still did not remember what really happened.

I only started to remember when I had my tracheotomy removed. I don't remember the exact date when I remembered everything, but I remember that I was already talking, with a lot of shortness of breath and difficulty. I had already been through surgeries, it was probably more than a month before that. I started to tell my aunt fragments of what happened, little by little, when they would come up in my memories or nightmares. I remembered the

look of hatred in my cousin's eyes as he assaulted me. It was an evil look. A look of fury. He would stick out his tongue and clench it between his teeth as he hit me in order to put more force into the blows he dealt. The last thing I remember before I blacked out and lost my sight was that look of hate...

I have never done anything to him! That day I had not done anything to him, nor any other day, I have never done anything to him. We did not argue, we did not quarrel, I always treated him with great care and respect, I have never done anything! When I woke up from the coma, I did not know why he had hit me and I only remember thanking God that it was not my aunt who was already old and would not resist. I thought "it's a good thing it was with me", that's the way I thought.

My cousin was arrested red-handed and at the police station confessed that he liked me beyond kinship and that since he was unrequited... The lawyer claimed that he had an episode because he was not taking his medication. However, I do not believe this because he premeditated it, he planned it days before, on the way to my house he went to a building materials shop and bought the hammer to hit me, he waited for the right moment when he would find me alone in the house, he hid so that I would not see him, he waited for the chance to hit me from behind without being seen. For me and for the prosecutor of the case, it was not an episode!

It was very difficult to have to remember what he had done... I slept through the night holding the hands of my aunts who could not sleep, they spent the night sitting on a chair beside me while I shook their hands. Every time I woke up scared, I had nightmares, in fact, even today when I am very anxious, I dream terrible things related to him. Remembering what happened and reconstructing the

scene for my family, for the police and for myself was very difficult, but these were not the only moments of difficulty and suffering. The physical pain, the numerous surgeries and procedures afflicted my body, while the memories afflicted my soul. It was in the moments of intense physical pain that the outrage against what had happened to me arose.

It was a very long process, but of all the things I've been through on my face, the removal of skin from my wrist was the most painful, I suffered a lot. They opened the area of my wrist, about three fingers of skin and sewed it up leaving an open wound, like folding a sheet leaving the mattress exposed. In about a fortnight, my skin would regenerate, and a new one would grow to cover the exposed area. The doctors would then remove this newborn skin and reimplant it in the site where my eye was. The donor area hurt very, very much. The pain that I felt in the donor area, according to the nurses who did the dressing, was similar to the pain of a burn, so much so that I stayed in the burn ward. I listened to those people screaming in pain.

I stayed at the house of a cousin who lives in São Paulo, since I would spend a long time doing the treatment there. I went with my aunt to the Unidade Básica de Saúde – UBS (Basic Health Unit) and the nurses made the dressings around the eye that had been removed and in the wrist region from where the skin needed for my face was removed. Not all the nurses could uncover my face, one time, one of them got sick when she saw my face, she had to leave and ask another nurse to do the dressing.

The daughter of the cousin who hosted me is in the health field and started to dress me personally. The pain was intense and those were the moments when I most resented it, I asked myself why he had done this to me. The rage emerged at the time of the physical pain. Then I stopped questioning myself and just thanked for being alive, the anger was because of the intense pain, that day especially, a pain that I do not wish for anyone! Because of so much pain, I decided to stop the surgeries. The doctors wanted to continue, even to put a prosthesis removing a little bone from the hip to re-implant in my nose because currently it does not have the bone and cartilage, nothing. I can't breathe through it, I can't smell, I lost my sense of smell too.

They made a layer with a cavity trying to give a depth to the shape of the eye, but it was not possible to make an eyeball.

I decided that I would not undergo any more surgery if it was only for aesthetics. I continued with the procedures that would allow me a better quality of life, such as treatment with an occupational therapist. The doctor said my hand would not return to normal, but I tried very hard and it came back. My hand is numb, but I can do my everyday tasks and work with massage.

My face has lost expressions due to lack of skin, if I try to make any expression of angry or a grimace, I can't even if I try very hard. The stretched skin retracts and I can't make the expression, no matter how much strength I put into it. Sometimes I'm serious, but people think I'm smiling. In certain situations, because I have stretched my skin to the extreme, I can't make facial expressions like serious, angry or sad.

As I matured and became more discerning, I made choices about which surgeries and treatments were worth the sacrifice of pain and effort and which were not. So, the assault was something sudden, out of the blue, quick, but the post assault period was very long, I went through a lot. The most impactful thing for me was not being

able to see myself and not being able to see a person. However, I still kept a great hope in relation to the eye that was not torn out ... the hope of seeing once again...

## And that was the day Beatriz died...

Returning to my parents' home was very difficult. My aunts' house was my world and my desire was to go back there after such a long and painful period in hospitals, relatives' homes, surgeries. Perhaps because I thought that going back there would be the same as going back to what I was before, and that wouldn't be possible anymore. However, that house was what I knew as a place of warmth, tenderness, respect, and it was no longer possible to enter that environment without being tormented by memories and fears.

That was a year in which I had a lot on my mind. The first year after the assault, I was hoping to see again. I spent a year hoping, believing that I would see through the eye that was not torn out. My friends visited me, showed me photos, reports and said, "I'll save it for you to see later" and these words fed my hopes, I lived with that expectation, the certainty that I could recover at least a part of what I had, of what I was. Despite the hope and belief that I would see the world again, it was also a year of anxiety and uncertainty, not knowing how my life would be if the worst happened and I could not see again.

However, for the most part, my expectations were positive, after all, I had lost one eye but still had the other. The pupil went down from the centre. I imagined that they would lift the eyelid and with this, I would see again.

The months went by and with them went my anxiety, expectations, and plans for when the nightmare and the darkness would end. When exactly one year had passed, I went for an ultrasound of the eye. I sat in front of the doctor with joy and hope and was surprised by a cold, direct and incomprehensible question: "Do you know Laramara?". I said yes, and the doctor continued, "And have you done any mobility courses?"

I had already heard about Laramara, which is the Brazilian Association of Assistance to the Visually Impaired, when I received a visit from members of the blind association of my city. Recommended by the doctor who operated on me, they came to give me support, guidance, indications of courses that would facilitate my new life and asked if I knew Braille, to which I promptly replied that there would be no need, since I would soon be able to see again.

Anyway, the doctor told me that it would be good for me to take some courses at Laramara, which made me feel weird and uncomfortable, I didn't understand why I had to take such courses since I would see again. He gave me the result of the ultrasound and referred me to another doctor who was much plainer and more precise.

The other doctor explained that there was nothing he could do for my eye, neither in Brazil nor abroad, there was no one who could do anything for me to get my sight back. He also said that he would advise me, with the same advice he would give to his daughter, that if someone wanted to mess with my eye, for me not to allow it. That maybe in four or five years' time it might be that with the advances in medicine, something could be done, but that at that time there was not. Eight years have passed and there still hasn't been any advance that could change this situation.

My aunt Bela and I were present at the moment of the news. I came out of that office in a panic. I sat on my aunt's lap and a hole opened up under my feet. A woman bumped into me and I felt like hitting her and taking it out on someone else, I felt like bashing the world, shouting, swearing, demanding justice, turning back time, everything!

But then my aunt Bela started to cry with me, a painful cry of someone who seemed strong up to that moment, but who would not resist any more. I couldn't bear to hear her in that state and I had to be a little stronger, for both of us... I stopped crying, I became quiet, I stopped crying on the outside, but I kept crying on the inside. I couldn't bear to listen to my aunt's painful weeping. I remember that on the way home she was crying and sobbing, and I consoled her and asked her to stay calm, but in reality I felt like screaming. I silenced my crying, I stifled my pain, I cried only on the inside. Of course, when I got home, I lied on my pillow, alone with myself, it was a different situation, so I could cry without being seen or heard.

It was not easy to come home, face my family, my mother, Aunt Carina, and say that I would not see again. I WILL NOT SEE AGAIN! This part was very difficult because how could I see all my dreams crumble? From then on, I had no more dreams. No more! They were simply over. What would I do with my life? I wasn't Beatriz any more, Beatriz was over. Deep down, the Beatriz that I knew I was, independent, dreamy, active, died right there... at that moment, even though I didn't die, she was gone with my blindness.

#### Hi, it's still me... Beatriz...

The psychologists said it's two years of mourning, just like when someone dies, and they were, indeed, two very difficult years to get back on my feet, rebuild and reinvent myself again. I was used to seeing the world, and my mentality was that of a seeing person. It is completely different to someone who was born blind, it is another situation. Little by little, I was trying to learn to look at the world in a new way.

At the beginning, I received many visits from friends, relatives, and even strangers who wanted to know how I was. People cried profusely and I, embarrassed and even frightened in many occasions, only consoled them, asking them to be calm, that everything would be alright. In reality, I myself did not yet know how things would work out for me...

One day, right at the start, when I returned from São Paulo to spend a few days at home, I was in the living room talking to a visitor, and they called me to go to the kitchen. When I got there, there were people everywhere, friends who came to congratulate me on my birthday, they sang Happy Birthday, it was a surprise party! That day I got to know everyone, one by one, through touch. I missed one or two people, but most of them I recognised by touching their faces. As the loss of sight was something recent, I still had their faces in my memory. They were all there and at that moment those people were very important to me.

Time went by and everything changed a lot, soon the visits became more and more scarce, the curious people already started to forget about my case, the relatives went on with their daily lives of work and hurry, the work colleagues lost contact, the friends no longer had anything in common. My life alone was frozen in time. Only a few friends remained by my side, the true ones and those who remain until today, besides my parents, sisters, and aunts. I suffered a lot with the loss of friendships because I had many friends, from the bakery, from the neighbourhood, from work, from my school days, in short, they all disappeared after what happened to me. I didn't expect that it would be like this, that I would become invisible, that I would be forgotten even though I was still alive.

Alessandra was one of those people who disappointed me so much, whom I believed to be a true friendship, but who could not resist adversity. We were very close, she was always at my house, I used to stay with her son on my Sundays off because he loved being with me. One day, I was at the supermarket with Elis passing by at the check-out and Alessandra and her family eating at a table beside her. They finished their meal and left the table at the same time we left the checkout. We walked behind them. She looked back, I still didn't know they were close, I passed them and when I got to the car, Elis said, "Beatriz, we passed a friend of yours". I asked who it was and from the description I knew it was Alessandra. Elis said she and her husband were there, and they looked at each other after staring at my face and pretended not to know me.

That gave me an inexplicable feeling, of anxiety, of anger. The next day, I sent her a message: "Alessandra, was that you in the supermarket yesterday?". She replied, "Yes, Beatriz!". I continued, "But, why didn't you say hello to me?". She answered, "I was with my husband and so you know how it goes...". No, I didn't, and I still don't know "how it goes...".

She apologised, and I said it was OK, however, inside I felt awful about that situation. It was over. I should have asked the

question "If I could see, would you greet me?" These are situations that sadden me because they were people who lived with me intensely. Today I don't talk to her anymore, I excluded her from my social networks. I don't hold grudges, the days go by and I calm down. But it was her birthday and I sent her a message on *WhatsApp* wishing her well and congratulating her. She never replied. So, I deleted it because it was doing me harm, and the friendship ended, we lost contact. I don't see anything anymore, and I leave her there in her corner, that's what she chose, and I don't know why.

On another occasion, Antonia, who lives here at the back of my house and grew up with me, did something similar. We were sitting at a gas station, I was with my sister Juliana and I felt that there was a person next to me. Antonia was talking to Juliana, telling her news about her life. At a certain moment of the conversation, Juliana told me who was the person next to me. I was stunned: "Antonia?" She answered: "Yes Beatriz, it's me, Antonia". She was next to me, and she hadn't addressed me, as if it was difficult to talk to me and say who it was. In these situations, I get really angry because she was next to me, I was there. How long we had known each other? It's as if I was nothing to people.

Beatriz feels that there are people who discriminate against her because she can no longer see. She says that there are people she knows who the person is, she recognizes them by their voice, but they don't greet her. Even people from her own family, who have seen her passing by and have not even called her. She can't see, so if the person knows that she can't see and sees her passing by, they could interact with her by saying, "hello Beatriz, I'm here, how are you?". She feels this, she feels this a lot, and she notices it, I've even noticed it myself. She

gets very sad, she says 'Oh, just because the person cannot see, the person has a disability, do they have to be isolated? It is not like that...' She does feel it. Even we are saddened, sometimes we forgive them because we want to believe that the person really did not see her, did not notice her, so we give them a break. The hard thing is that she knows the voice, right? She knows who it is, on this aspect she resents a lot, yes (BELA, Beatriz's aunt).

And since then, I go through situations like these almost daily, whenever I go to the supermarket, restaurant, shops, walking down the street. I count on the support of my family and a few friends, and that's it. I try to stick to what makes me stronger and what makes me feel alive, useful in some way, such as the birth of my niece. Caroline's birth happened at a very important moment in my life when I was in the process of acceptance and rediscovery. Caroline was born a year after the assault, and since then, she has helped me to have more strength. At first, when I gave that baby a bath or did anything for her, I saw myself as a capable person again, I could understand that I was still me and despite the disability, I still had something of myself, I felt that I could help someone.

I felt the same way when I was doing something for my aunt Carina, who had fallen ill. Aunt Carina was already old when I was assaulted. Before the assault, she cleaned the house, washed the clothes, did everything, but what happened to me was so traumatic for her that she gradually withered away until the day she died. She was afraid, she was traumatised as much as I was because she saw me like that. I couldn't go into the room where it happened, so she would sit in the living room and I would stay in the area outside. She would tell me, "Turn on the light, Beatriz". I didn't need a light, but she

would insist "*Turn on the light, Beatriz*" and I would turn it on because of her, she didn't want me to stay in the darkness outside the house. In the last days of her life, it was me who gave her a bath, put on her clothes, helped her with everything I could. In those moments, there was nobody doing anything for me, invalid, limited, blind, but it was me who was doing something for someone I loved, someone else needed me and not the other way around. This way, I was able to learn and discover all that I was still capable of!

It was a process in which I needed someone to give me strength, there was always someone reaching out or taking my hand so that I would not give up. God put people in my life when I needed them most and with unexpected words that strengthened me again and kept me going.

## **Disability**

I have tried to see my face several times. I ask God to show it to me in my dreams, but at the same time I am afraid... I have seen myself with only one white eye and the other normal. In my dreams I have managed to almost look at myself in the mirror, but just as my face was about to appear I would run away, catching only a glimpse of it. When I touch it with my hands, inside, it's not possible to imagine how it is because I don't have that image stored in my memory.

If I had seen a face without an eye before going blind, maybe my mind would bring back some image of what I am today, but since I haven't, it's hard to imagine. Even though I don't visualise the figure of a face like mine, I know the impact it makes on other people when they verbalise expressions of fright or pity. On one occasion,

the small son of a friend cried in despair and terror at seeing me without glasses, calling me a monster. It is in those embarrassing moments that I can imagine how disfigured it is...

Some people have told me that they would have died if something similar happened to them. When you put yourself in the place of a person, it's not the same as living the situation. You can try and feel it, try and imagine it, but each person will have their own way of experiencing it. The pain that I feel on my face today may be nothing for you, or it may be much worse than it is for me. For each human being it will be different, even if they go through the same situation, it doesn't mean that they will feel the same. But I am absolutely sure that the same way God gave me strength, he would give it to other people as well. Before telling the challenges of a life with disability, I made a summary of the facts that for me have been remarkable in my life history...

#### (Line of ("Life Line") instrument)

- 2003 Working in the bakery
- 2004 Good year, I started dating.
- 2005 I started taking an English course, computing, and sugar and alcohol.
- 2006 I did a course in Massage.
- 2007 I had a serious motorbike accident.
- 2008 I finished the Foodstuffs course, graduation, what a joy!
- 2009 Internship in Vinagreira. I went to the beach.
- 2010 New job, new plans.
- 2011 I was assaulted.
- 2012 Birth of my niece, a joy in my life. I found out that I would never see again.
- 2013 I met the Association for the Visually Impaired.
- 2014 The aggressor got out of jail and went to a mental institution.
- 2015 I cycled alone in the institution.
- 2016 I took a braille and computer course.

2017 - I sold my bike, how sad. I attended a lecture for blind women. I started a course in Massage Therapy. I did a course in Relaxing Massage and Crochet.

2018 - The aggressor is out of the mental institution, my peace is over. The aunt who saved my life has passed away.

2020 - I agreed to participate in this research.

#### The world is not for us...

When society looks at me with pity, considers me incapable, and I realise that the person's words are of great pity, I always try to deny it, to change this "poor thing" view about me by saying how well I am. What helped me in the process of accepting the disability was firstly God, I would not have achieved anything without my faith, it was my foundation. Then family, a few friends, psychologists, psychiatrists, a set of things that helped me to get this far because the mind is the most difficult part to cure. Some things have changed in my view, others continue the same, although people no longer seem to recognise me.

I think Beatriz first of all overcame the problem of lack of sight within herself. I think it is a matter of acceptance, I think she accepted 'I am like this, and I will have to adapt to live' and this was primordial for her life. She never complained or complained, I never saw this woman say, 'Oh, I'm blind, woe is me', I never heard her say things like that. She never cried, she never complained! Personally, I don't know if I would behave like that if I were her. She had a very good acceptance, her psychology was worked on. I always tell her that this is a slap in the face for many people because there are people who find obstacles in everything, to work, to leave home and with

Beatriz, the obstacle does not prevent her from living (Ivana, Beatriz's client).

Interestingly, I am more vain today than before I went blind. When my nails and hair are not done, I ask Juliana to help me, to take me to the salon because I depend on others to do it for me. Before, I used to go to the salon and do my hair... ME! Now I don't, I depend on Juliana or someone else who can take me. I learned to be more vain than I was before, that is because the blind, the handicapped are much more seen than a normal person. If a person without a disability enters a market, they take what they want and go unnoticed. The disabled person does not. When a person with a disability enters, people look and follow them with their gaze, they stop what they are doing to observe them. Sometimes my sisters say "For God's sake, get dressed, if someone comes in here they will think we don't take care of you", so I go, change clothes, get dressed, more to please others than for myself, knowing that I am the target of observations and comments. For me, what really matters is the content of what I'm going to talk to the person and not how they look.

In my daily life, I even forget that I am blind. However, there are situations in which blindness startles me and I get angry, I question myself, I rebel, normally situations provoked by others. We were at the country house for the weekend, I wanted to get something from the house, my sister Paola was there to guide me. There was a climb, and I was tapping with my walking stick to find my way. She said, "Be careful! You will hit the others!". I answered, "Paola, how can I hit someone when I know that this is just a climb, there is nothing and there is no reason for anyone to stand here?" A man who was

passing by and heard it said laughing, light-heartedly, "You should really hit them, they should get out of the way!".

Statements like this one from Paola show me that people don't put themselves in the shoes of the disabled, as if it was only my duty to adapt to others. I get aggravated when someone is giving me directions and suddenly picks up my cane and abruptly takes it in another direction. My hand follows the sudden movement, throwing me off. "Oh, Beatriz, there are people there!". This upsets me inside, and I think to myself "Gee, it's as if the world is blind, and I'm the only seer at this moment, it's me who has to dodge people!!!". I get so irritable that I feel like throwing the cane away.

If I am trying to orient myself, the cane at that moment becomes my eyes and I cannot use it if they constantly take it from me or change its direction. The first thing people do is pull out my cane, they take it from me without any warning. Then I hand it straight away to the person who took it and when they say "Here's your cane", I reply "No! You want to use it!". It makes me angry. I got so angry once that I let go of the cane by dropping it on the floor inside the market. Elis tells me she does this to avoid me bumping into something and breaking it. On those occasions, I cut her some slack and in places full of things I take extra care because I know I can break something. On those occasions, I hold the shoulder of the person accompanying me rather than use the cane. It has happened that I knock over certain things in the market.

In fact, I got very angry with Elis for something like that. We went to a shop, and I was looking at cups. I found a cup that looked beautiful. I finished looking at it and went to put it back and ended up knocking it over on the shelf. Although it didn't fall to the floor or break, Elis got overly upset, treating me like I was a child and

needed to be scolded. My face must have been red from embarrassment, from being flustered, from the way she spoke to me. I felt like I was nothing, a child, as if I couldn't handle myself, even though this incident could have happened to anyone.

She replied that I would break it and would have to pay, so I should stop messing with it. I remembered a friend from the association who broke all the jars of candy that were for sale on a stool in the middle of a pavement, and I became even more nervous. The difference was that I hadn't broken anything and anyone could have knocked the cup off balance, but the issue was visibly because I am disabled. I felt really bad because of Elis' attitude, the only reason I didn't cry at that moment was because I held myself together, breathed and kept quiet.

If I could still see, it would be another situation because I would simply turn my back and leave her talking to herself when she hurt me. But my disability prevents me from doing things, from reacting as I would like to and this irritates me, the disability prevents me from being myself. I have always been like this, if there was an argument involving me, I would just turn my back and leave, I never stayed in this kind of situation, today I have to stay and this makes me very nervous. I want to resolve my things and I can't leave without needing others, and this makes me anxious, aggravated.

When you become disabled it is always the other person who does it for you, I am dependent on the other person, if I want to go somewhere they have to take me. It seems that when you become disabled you no longer have your own life, it seems that you are no longer your own person, you no longer have your own opinion. You end up doing things you don't even want to do, you lose the voice to say what you want, whether you want to do that or not. For example,

as if I said to you (Researcher), "I'm sorry, but I don't want to do this interview" and you answered me "No Beatriz, do it, you have to do it!". "But, Ana Paula, I don't want to." "Do it anyway!". My opinion doesn't count anymore. I'm blind, but it's as if I also don't speak besides not seeing, as if I don't have any more reasoning, voice and choice, so I became nothing to people.

Each person has a personality and their inner self follows, but it seems that after you go blind, irritability and restlessness become greater. The fact that you can't do certain things makes you more nervous. In these moments, people say "disabled people are so irritable", the wheelchair user or the deaf person, but it's because we can't do what we want to do that we become more vulnerable. The world is not for us. People can't see us and can't hear us, the streets and pavements are not accessible, the whole shape of that world is for the sighted. We are considered inadequate, incapable, burdensome and at the same time we are seen in a template where everyone has to have the same abilities. I mean that if a person with blindness is able to do a certain thing, I have to be able too, as if we are all the same! "How come you can't do it?". I carry a burden for being disabled, I have to prove that I am capable of doing that. It is not enough to be blind, you have to do it. You have to be capable and yet, you are labelled as poor thing and incapable.

But, I have to understand that I can't do it anymore. Occasionally, I plan, if I have to go to the dentist, for instance, I plan to call the Uber here and ask them to drop me there, I think about doing this, but I've never done it because the fear immediately comes along with the planning. I think I would be able to go alone just to my hairdresser's, which is very close, it's a block away, and I would be able to make it by myself. Still, of course, my aunt would be

watching me from the sidelines. When I go out even here on the pavement, just to turn around and enter my aunt's house, I know she is watching me, I feel her presence. Once, she assured me that she would let me go alone, that she would give me a vote of confidence and not keep watching me. However, when I went to cross the street, she shouted, "Watch out for the tree!".

I understand that on certain occasions it may be that I restrict myself, there is also this side, many blind people restrict themselves, they think that they won't be able to accomplish certain things, and they end up not being able to! It is as I mentioned before, each person has their own gift, your gift is certainly different from mine, they are different situations, but nothing stops the blind from trying and seeing if it is for them. Try and see if they like it or not, and that's fine, but don't even try because they believe they won't be able to because of blindness... To try or not to try involves a lot of fear, fear of frustration, fear of what people will say about you, fear of another defeat, there are many issues involved. I no longer have one hundred per cent of any of my senses. My hand movements have been impaired, my sense of smell has been lost, my sense of taste has been compromised, my hearing too, so all my senses have been compromised apart from the loss of my sight. Still, I work and try with what I have.

## I'm no longer the Beatriz I was before...

Today's Beatriz is... a warrior! (laughs). I'm joking, people often call me a warrior, but I just consider myself determined. I find that today I am much more determined in some situations than I used to be. Today, I say I'm going to do something and I won't give up

until I get it done! Although I have always been persistent about things, now I am more determined, I can achieve what I want and go all the way, I try and do it, even if in the middle of the way I throw a fit or get angry, throw the cane to the ground (laughs) even if I do these things I will achieve my goal. Today, I am also more sensitive, sometimes more rude, I am not delicate at all depending on the situation.

The situations that commonly make me irritable, sensitive and unkind are those in which my own family forgets my condition as a person with blindness. In my point of view, Paola, for example, cannot understand that I can no longer see, that I have a disability. She does not want to accept it, she thinks I am the same as before. But, I am no longer the same person I was before, today I have a limitation.

I know that nobody is fit to deal with the disabled. Nobody! If a disabled person arrives and stays in your home, you will also be a bit overwhelmed, this is normal. But time goes by, and you have to adapt to the disabled person, getting to know their needs. They don't see me as a blind person. They don't see me, they see me as the Beatriz of before. Sometimes I even want them to see me like that, unconsciously I try to be the Beatriz of before. That Beatriz who could go out without requiring help from anybody or having to ask for things in so many situations, but no matter how much I wish and try, I can't be the same person or perform the same way.

At my parents' house, they have not yet adapted to the blind person; on the contrary, I am the one who has to adapt and overcome all the obstacles they impose on me. They move things around and don't tell me. Paola keeps changing everything, and I only find out when I bump my face or legs on something. I have to take a deep

breath in order not to argue. But, many times I bump into something, I get hurt, I get angry, nervous. Paola has the habit of changing the position of the bed in the room. When Caroline would fall asleep, and I would carry her to bed, I would often put her lying on the opposite side of the bed to the headboard because of the changes in the furniture arrangement without any warning. A little while ago I went to take Caroline to her room, and when I arrived with her in my arms and went to put her on the bed, I felt Paola's feet on the place that would have been Caroline's, and I said "But have you changed the position of the beds again? I ask her to let me know when she moves things, but she doesn't.

They used to leave the motorbike in the middle of the yard, right in the passage to my aunt's house, I used to fall and step on the motorbike. They leave the shoes on the doorstep and I have to pick them up every time so that I don't trip and fall. Every day I have to do the same thing, pick up the shoes, find out where the furniture is in the room, but I have nothing to do but adapt to this.

If I clean the house, of course it's not the same as cleaning for someone who can see, but I do my best, I try. How many times Paola has come and redone everything I had done, and that upsets me and discourages me. I make so much effort to do things, it is difficult for me to do everything I did before, and she complains that it is badly done. It is more difficult to live with Paola, it may be that for her, it is very difficult to deal with my disability and the tragedy that happened to me, it may be that I bother her with my limitations and fears, I do not know what goes on inside her head. Maybe it is her way of not wanting to face reality and accept that her sister is now ... a person with disabilities.

It is very difficult because we want to change the perception of others, but it's no good. My mother always repeats the phrase, "I did not have a blind daughter!". Very often my mother is giving me directions, and she stops abruptly in front of me and I just bump into her or trip over her. She shouts angrily, "Ouch!". It bothers me because it feels like I'm wrong. I think my mobility teacher should give my family a lesson, the first step should have been to instruct the family.

I wish I could obstruct their eyes so that they can see what it's like. It's not the same anymore, it's very different, these are situations that sometimes I can't change because deep down I think they... Sometimes, I think they understand the reality that I don't see, but most of the time I realise that they don't believe it or they don't accept it. Today, I was sweeping the yard and I noticed that there was someone at the door, I asked who it was, and my sister replied snidely "It's me, Paola, Beatriz! Who else could it be?". I replied, "How would I know who it is? I can't see". Then I kept thinking about it... could it be that they don't understand?

I even plan to one day enter the room at a time when she is sleeping, in the dark, touch her feet, and then she will ask me who she is, and I will answer in the same harsh way so that she feels what it is like for me so that she understands that now I live in the dark, so when I ask who she is, it is as if I am seeing with my eyes. On another occasion, me, my niece Caroline and Juliana spun around, we held hands, they had their eyes closed and after a lot of spinning I proposed that we find the door to the room. I felt great because I found the door quickly. All I have to do is identify any part of the place where I am, and I find my way around quickly because I already know the place. Now she, being a sighted person, doesn't know how to work

with the part of hearing that we have to use to orientate ourselves. These occasions, when I can feel superior and not at a disadvantage, bring me much satisfaction.

It is difficult for people to understand the needs of this new Beatrice, and they almost always interpret it as me being annoying. Yesterday, Elis and I had a fight because I was trying to tell her something important about a family matter, and she was listening to music while I was trying to talk. Elis likes lots of noise, loud music and I also like music, but when I am talking I don't like it because it gets in the way of my attention, since I only have my hearing, which is also impaired.

We started talking, and I asked her to turn down the sound, she turned it down a little, but not enough. I said that when it was quiet, I would tell her. To annoy me, she started to sing the song even louder, so I refused to talk, I wouldn't talk as long as the noise was getting in my way. When you were reading the summary of our previous meeting I remembered this situation... if I suddenly exclaimed "Blimey, I'm blind, I only have my hearing, the noise is getting in my way" I would be called ignorant, she would call it a cheap shot!

Sometimes I really go for the cheap shots, but when I do, it is because I am already at my limit, in certain situations I have to be emphatic and play dirty. In that situation with Elis I wanted to avoid being rude, I didn't want to speak this way, but I could so that she would understand that it bothers me. Sometimes, at my mother-in-law's house, I always turn the sound down because if she comes to talk to me from behind, for example, I don't understand, and I get even more annoyed.

The other day at my mother-in-law's house, the television was so loud that I couldn't wash my hands or go back to the living room, it seemed that I was in a place where I had never been before because the noise was so loud in my head. I sat down on the sofa and said to her, "Wow, I seem to be blind today!". My sister-in-law has a problem with me because she thinks I can see. They say that I follow them with my eyes when they move, and this makes them suspect that I can see. They keep walking, and I follow them with my eyes because my hearing guides me. When I told them that I was feeling blind, they even laughed because deep down they believe it. I explained, "not that I can see anything, but today I can see less!" (laughs) They answered, "Oh, is that so, Beatriz?" My mother-in-law came home on Sunday night, and I was sitting in the living room listening to an audiobook when she came in and exclaimed, "What are you doing in the dark?" That's one of the things I hear the most: "What am I doing in the dark?" I don't answer, I just smile. At one point, my father has asked me, "Why are you making food in the dark?" I get an indignant look on my face. If I kept all the lights on, people might even suspect that I'm not blind, but I don't need lights.

Many times, if everyone leaves the house, and I am here alone, I turn everything off, I don't want the sound anymore so that I can pay attention to what is happening outside, at the gate... I can pay more attention. Paola wants to hear the sound too loud, and I ask her to turn it down. She says, "For God's sake, you're a pain in the neck! Why don't you go inside?". I go into my room, close the door and listen, but, depending on how loud it is, I can't do anything! My mobile is digital, and I depend on hearing to type or receive something. It's like the sound blocks my vision and I can't do anything else. These are the things that happen in everyday life, and they make me think, they

don't put themselves in my place, they forget that I really don't see. Just this morning, I was putting the stretcher in the room and I hit my mother's leg. She asked me: "Beatriz, can't you see that you are hitting my leg?". I said, "Mum, I really can't see!!".

In certain situations, I think people do forget. Because I pay attention to the voice and look in the direction of the person speaking, they may forget that I can't see. There are blind people who are quiet, look away while you speak and don't articulate with their head, so the fact that I do that makes people forget that I can't see. However, when your family forgets that, it's more complicated because I think, "Well, if they forget, who's going to remember? If they can't put themselves in my place, who will?". It's in those moments that the future worries me.

#### An uncertain future

The other day, I was talking to my niece Caroline, who told me that she had a dream of meeting a television presenter and some characters from the children's soap opera she watches. Caroline asked me what my dream was. I stopped, thought about it, and answered that I had no dreams. She insisted, nonconformist, asking me if I didn't dream of anything. I spent the whole day thinking about this, about which dream I would have. Even though I reflected so much, I could not think of any dream. I would like to do a bamboo course (massage), but I think this is a goal and does not have the strength of a dream, as I had before with the motorbike or with college, today I have no more dreams...

Not that, for me, it is sad to stop dreaming as it may seem to other people. It is not sad, not having dreams may not be something negative. In the old days I had the dream of being a psychologist, I had it, but it didn't work out and that was OK. Today, when I manage to achieve something I want, something that seemed difficult for me, this already makes me happy. It makes me have happy moments, and that's enough for me.

Dreams have given way to real concerns in my life. I think a lot about my future, about old age, I think a lot about what it will be like if I am alone. I don't know if I'll still be with Elis, if I'll have someone to look after me, or if I'll be in a home. I am not afraid of the future, I just worry about it. I think that because today I live with constant uncertainty, in the future I might be afraid of being alone, living without a mother, father, or sisters. Because one day everything ends, nothing is forever. It may be that I will die first, as it was meant to be. I also wonder what it would be like if I stayed in a place where only blind people lived, all old and blind, in Minas Gerais there is that kind of place. I think more about worries than dreams!

I consider my future uncertain. I think that disability makes you think in this way, "What will happen in the future?". Because when I had everything, I knew that one day I would be old, and would be in a situation of old age, of fragility. But, imagine you being blind in that same situation. Having a disability, needing someone. I know that there are many elderly people who live alone, just like the man who came to visit me today, who is 91 years old. But would I be able to be alone with my disability? Because with old age, hearing goes out, everything goes down. I think how difficult it would be for me to be deaf as well as blind, for example. So, I think that if I were to become an old lady, in the future I would stay in a home so that I wouldn't disturb anyone, or be left alone at the mercy of my own fate. While the uncertainty of the future does not arrive, I try to make my

history in the present, seeking as much knowledge and independence as possible, whether in my personal or professional life.

## At first, it was just another course...

I remember well the lymphatic massage course I took when I still had my sight. The eyes made all the difference in the way of learning, I could visualize the person's body. In the theoretical part it was also all different because I had more possibilities to study independently, besides the classes, I could read the books, handouts, do research, it was all much more comprehensive and accessible. It was much easier to do the course seeing, it was very rich in this aspect. When I was seeing I couldn't feel every human part as much as now that I'm blind, today the touch is very different because before I was based predominantly on what I saw, even touching, I trusted my eyes, now I really trust what I'm feeling. The person who sees believes in what he sees, I believe in what I feel and touch.

At that time, although I believed I had a special vocation for massage, since my friends would ask me to massage them even before I thought about the course, I already had a job and an infinity of tasks and possibilities. As I was very shy, I left massage aside and started to dedicate myself to other things and plans. I had a masseuse course, but I wasn't thinking of making a job out of it.

I only really dedicated myself to massage when I started to take the course again, already without sight. At the beginning, it was just one more course for me, as I already had a basic notion of what it was, I decided to take one more, but with no intention of it becoming my profession, after all, I was already receiving a pension. It was simply one more course to occupy my mind, to pass the time.

I started to take the course, and I became interested because I realised that it was much more than what I imagined it could be, it was more intense than when I did it with my sight unimpaired. Now I had another world view and I also identified myself with massage therapy. Being able to help others with therapy, to be of use to someone even in my current condition, was decisive for me. It is very sad to realise that people think you have become just someone who needs help and never someone who can help.

I started to worry about questions such as, "What will my future be like? What can I work with and how? What am I capable of achieving without the help of sight or other people?". Massage became again a possibility of work, income, independence and above all, a possibility of fulfilment in helping other people! Before these reflections, I did two new courses of Relaxing Massage and Therapeutic Massage. Yes, it was much more difficult to learn, to memorise, I had to be very persistent, many times I did not feel like going to classes due to so many obstacles.

Despite the tiredness and difficulties, or even the lack of enthusiasm on many days, touching a body after being blind was a very good sensation, of discoveries and of looking carefully because most people only see superficiality when they rely on sight. I can see that the skin has an apparent bruise, but I don't perceive a lump hidden behind the bruise unless I touch it and feel it. During the massage, if there is a lump I will feel it, but if I relied entirely on my sight I might not notice it. When I could see, I didn't fully feel arms, hands, legs, every part of a person's body, it was something based only on looking. Re-learning to look beyond sight, to feel, to touch, is what gave me the strength to continue.

Besides me, other people with the same disability were enrolled, it was a course offered specifically for people with blindness by the initiative of a teacher of the association. To give this course for people with blindness was an old dream of professor Wagner ever since he graduated as a massage therapist many years ago. The class was formed of people with low vision and blindness, only the teacher was a sighted person. It was a course mediated by the association for the disabled. The city hall provided a space, they got some stretchers and we had the classes. Many times, this teacher had to use his own resources so that our needs could be met.

I met Beatriz in the association who accepted my proposal to teach the course as a volunteer, since they couldn't hire me at that moment. Beatriz arrived intending to do the course, and she persisted a lot, she attended all the classes, she hardly ever missed them, unless she had some medical appointment or something like that. Beatriz did all the courses and the result is visible, nothing would help if she simply wanted to become a professional in the area but lacked the dedication to attend the classes. The greatest merit is undoubtedly Beatriz's dedication, effort, and commitment. In each class, three or four students stood out as the best, and Beatriz was always among them. I would ask the students to apply the massage on me, to train and for me to notice if they were getting it right, to feel the pressure they were putting on. Even though I did not learn it that way, I taught it that way. In the practical activity, Beatriz was always among the few who stood out and did it right (Wagner, teacher of the massage course).

Originally, we were fifteen people between blind and low vision. In the end, only three blind people graduated and, out of these, only I work with massage. The group of blind students is not united and not interested in things, that is the truth! The blind are not united, when they start they are not interested, they complicate things and I get very aggravated with this.

The greatest obstacle in this course was the fact that the majority were taking it just for entertainment and not to actually learn a profession. There were few who really had the gift for massage. It was also challenging to deal with such a diversity of needs of each person, after all, it is not because we are blind that we are all the same, we have different difficulties and abilities.

For example, since today hearing is all I have, if I am talking to you and there is noise and side conversations, it bothers me. Side conversations of those who did not take the course seriously prevented me from concentrating. There was also a student who, besides being blind, was deaf, wearing braces, so imagine how difficult it was. The teacher spoke and for me everything was fine, but when the teacher asked her a question she answered that she was hearing very low or almost nothing. The teacher would start the class again from the beginning, and we hardly went any further.

The teacher taught each student by touch, we lay down in ventral, dorsal, right and left decubitus, we knew the basic principles. Wagner started from the beginning talking about the three points and showed each student with his own hands which were the three points. The course took a year because he had to teach the students individually. In each class, he had to recap what we had learned in the previous class by doing it in practice again and only then presenting the new content, and so on. It was our way of memorising the content

since we didn't have the resource of reading a workbook. Only two people in the course knew Braille, the rest did not. My particular strategy to memorise, besides what the teacher did, was to practice at home with people. The teacher used to tease us telling us to do it on dogs, cats and teddy bears (laughs). I used to do it on my family members. When I couldn't remember I asked someone to read the workbook. It was difficult to memorise certain things, like all the points and the movements.

Beatriz had no difficulties, she even helped, she gave rides to other people, she always brought one or two more colleagues with her. I did not imagine that it would become their profession, I wanted to teach without expectations, I knew that this would depend entirely on them, I taught without expecting them to become professionals. I fulfilled my role of teaching the whole, from how to attend the patient to how to charge for the service, in short, how to receive a person, how to make an anamnesis form, how to offer packages, what and how to charge. When Beatriz said during the course that she was practising at home to memorize, I was very happy because there are six hundred movements, thirty movements in the arm alone, a long sequence and if you don't practice you forget. Mastery comes through repetition, through practice, so I asked them to repeat to me what they were learning. They learned this way, using touch and orality, I took each one's hand and showed the movement, the pressure, the people who could not be touched had to miss it because it was necessary (Wagner, teacher of the Massage course).

It took a lot of flexibility, creativity and adaptations for us to learn. During one of the courses, I learnt that I should apply the

technique through the cloth, without the person needing to take off their clothes. However, being blind, I would not have the full dimension of the body. This massage is ancient, it came from China, it is the *Anmá* technique and in royal times, the slaves who applied it could not touch their masters, so they applied it over the cloth.

Even today, there are people who do not like to be touched, depending on who is doing it. Wagner really wanted us to apply the technique on the fabric, but I intervened and explained to him that for us blind people, it is not possible! I explained why, and he ended up understanding that for us, it is crucial to have direct contact with the body, since touch replaces our vision. Wagner listened and looked at our learning needs and adapted the technique so that we could apply it without the tissue over the skin.

It was a simple course, but rich at the same time, for one year it taught a lot! Intending to learning more, I also went to the teacher's house accompanied by two other students who took the course seriously. This course allowed me to receive something very much in demand nowadays, which is the diploma. I know how to do massage, but I can only prove it by having a certificate. So, it was something important that I always thought about to prove my qualification. I thought that doing the recognised course and certificate would be indispensable! A certificate that proves that I am capable, that I am fit for work, that I have a profession. A certificate shows that I have really made an effort, learned, overcome and that I can be in the job market in the same way as other non-disabled people.

Beatriz is a normal person like the others, but she identified with the technique, she liked it and wanted to dedicate herself to it. I did not treat her differently from the others, but she stood out, those who gave up did not identify. She always asked me if I was right, if I was observing her, as a student, she was always more serious than the others. She knew how to play at play time, but she also knew how to be serious when she needed seriousness. Beatriz was special in that way, she was not flighty, but a dedicated student, hard-working. I always used to say that I would like to pass to the students in the training 100% of what I knew, but I could only transmit 80% and of that, they would apprehend 60% and apply 30%. Knowing that, Beatriz tried to make the most of it, she always worried about questioning me if she was doing it right, she was always correcting herself, always (Wagner, teacher of the massage course).

I have never been through a job selection after being blind, but I have blind friends who have and told me how it was. The preference will never be towards the blind person, but towards someone who doesn't have a finger or something like that, or even the deaf person is at an advantage because he sees and can do the job even though he can't hear. For the blind, it is much more difficult.

I remember that, back in São Paulo, I received the news that I wouldn't be able to see again, they said, in an attempt to console me, that I could work and that there were many blind people who worked in clinics. They just didn't tell me that these were exceptions, that they had higher education degrees or that they performed specific functions in the area in which they were trained. The blind professionals mentioned by the doctor who work in clinics in São Paulo have higher education and work in areas that do not require sight. I had a blind friend who worked in a factory in a big city,

producing crates. As he knew the job, he didn't need eyes to build them.

The doctors did not consider that I live in a country town, which is somewhat limited as far as inclusion is concerned, the visually impaired people in my town are working as what? They are begging on the streets! If one looks, one will not find people with total blindness working in my town. Maybe they will find someone with low vision, but not a person with total blindness. As I said, I have not been through experiences like these looking for work, but I know what it would be like from the experiences of friends who have been through it.

As nowadays there is a lot of eroticism about massage, it was renamed massage therapy, but I realise that the doors are always closed to professionals in this area. So, I pass all this on in my students' training, of the difficulties and obstacles they will find in this profession, even more so if they have disabilities and are seeking inclusion, I try to pass this awareness on. However, I have to show that despite all the obstacles, in the end it is rewarding, it is transforming, it is not a mechanical work (Wagner, teacher of the Massage course).

I always try to keep improving myself and never stop studying, as much as possible. Nowadays, there are many courses, even on *YouTube*, in which I could improve myself, but being blind, how? When I took the course, the teacher asked me to go on *YouTube* and look for some content. I found it, and it was no use because they simply talked as if everyone was sighted, how would I know where is the point he is pointing? You can't tell just by listening. When I wanted to research more about fibromyalgia because I was going to

assist a client with this, I needed other people. So, I required the eyes of Elis, Juliana, Paola, various points of view because they could not always explain what they saw, I needed various people for me to reach my own conclusion.

I told her in the first appointment that I suffered with fibromyalgia and then a remarkable thing happened, she started studying my disease and adapting the massage. She started to touch points such as the back of the neck, below the shoulders, knees and told me that she was studying the subject... and it's fantastic for me, I can't do without massage. She was adapting to my problem, she was studying how the massage would be for my specific pains and this was the differential that made me stay with her until today, I've been with her for two years now. I've been to other masseurs and physiotherapists, and they never did that, they never adapted the massage just for my needs, but Beatriz did. That was the big difference between Beatriz to other professionals I met. She mixes other types of techniques such as relaxation and instruments such as stones and this is great for me, I have been able to quit several medications because of the massage she does. It has been very important (Ivana, Beatriz's client).

She still has the desire to grow, to take other courses to deepen her knowledge. She would like to do a Reiki training course, but it is a two-day course, and she would have to go to another city, there are expenses, and would they accept a visually impaired person there? There is all this struggle. She would also like to do a bamboo technique course, and would the teachers be willing to adapt to her needs? Beatriz has a thirst for learning and if she had more opportunities, she wouldn't

miss out. I don't know what her family's possibilities are, but if she had more support, more help, someone to provide her with a car, suddenly, the Health Secretariat itself, which should invest in her training, give her the conditions she would certainly take advantage of all this. Beatriz is someone who deserved a support from the Government, a political support, a bigger support from someone (Wagner, teacher of the massage course).

Today, I am proud of my choices and of my journey, I am a certified, safe, qualified professional, and I work independently since it would be very difficult to enter the formal labour market.

## Few people want to fight for this cause, more resistance than help...

I was reading the introduction of your article and thinking how sad the reality of the person with disability is! The data from the Annual Social Information Report ("Relação Anual de Informações Sociais" - RAIS) show that the number of people hired is very low. Courses, universities, involve the work of many people, gee, a lot of things, and even if a businessman would like to help in an isolated way, he wouldn't have enough strength to move something for being isolated, and the handicapped person ends up giving up for not having the strength to fight. Few people want to fight for this cause. I was reading the article, and it got me thinking that, in the past, the Catholic Church saw the disabled as sinners who deserved to be isolated and to live off alms; people didn't even go near them. Nowadays, things have changed, but if we stop to think about it, even today the disabled are still left aside, they are not seen as sinners, but

they are seen as pitiful and incapable of making a living out of their work.

I even thought of setting up a team with Beatriz and two other people who also stood out so that together we could offer massage in a sports club and hotel in a nearby city, but they did not accept the idea well. They said they did not think it was convenient for blind people to be working with massage, maybe they thought I was trying to take advantage of their disability, which was not true, I noticed the capacity of these people and would be working together with them, I would also apply the massage with them, it would be an opportunity for both (Wagner, massage course teacher).

No matter how much people evolve, how much the world evolves, I believe that the disabled will never be seen differently, ever. No matter how much they fight, try, and I am sure that they will fight... in the end, only one or another will manage to get somewhere, most of them will give up. They give up because it is a tiring struggle. We have to fight, fight, fight to achieve something small. Everything is very bureaucratic and difficult for the disabled, perhaps with the intention of making them give up. Imagine how it would be to go to college? Very difficult! Very complicated!

The problem of work for the disabled... many of them want to, but have nowhere to work. It's what we always talk about between us, when a vacancy arises, it will never be for the severely disabled. In fact, a few days ago there was an ad for a shop that needed to hire disabled people, telling them to bring their resumes. But, a blind person, a totally deaf person or a wheelchair user goes there... see if they hire. They don't! They get those disabled people who only

"limp", so for these types of disabled people there is work, understand? But for a blind person or a totally deaf person, a wheelchair user or another more serious disability, they don't find work.

## In my work, I am the one doing something for someone!

When you can see the wonders and opportunities that your vision can provide, things get a little easier and with that, the chances of work end up being more favourable for those who can see. However, if you don't have the same vision, the disabled person sees their opportunity soon being taken by another person who has a very small disability compared to yours. How can I compete with someone who has low vision when I am totally blind? Undoubtedly, who would get the job? But that doesn't mean I should keep whining, I am much more than all that, and for that reason, I won't feel inferior.

Work ennobles the man, isn't that what they say? When I took my first massage course, I could see, and it was easier, after all I could read the books several times, the drawings illustrated the positions of each movement, the lymphatic massage showed me a wonderful world of knowledge where the human body is so big before my hands. However, it was in my second and third courses, now blind that I really found myself, massage therapy makes me enter an inner peace when I apply it, I think about how the body is so big and at the same time so small, the points that are relieved with a touch, but that can also be easily hurt with a wrong massage.

Being able to make my hands travel a path that leads the person receiving the massage to relief and relaxation, there is no word that expresses the feeling of being able to help others. I don't know if

everyone feels the same happiness and values touch as I do, but I would like everyone to feel the same pleasure in working in something they like, in loving their profession, in recognising it also as a gift. I don't want to stop taking new courses, even though I know that for the disabled things are more complicated, even so, we can never stop seeking new knowledge (**Text taken from the Self Report instrument**).

I could see this sensitivity in Beatriz, she evolved a lot, not only in terms of massage, touch, but also in terms of the energetic issue, in exchanging energy. I could see that she was passing on something good. She managed to understand that she was a vehicle that transmitted good energies, she didn't need to take a specific course to understand this. She didn't need a Reiki certificate, but she learned by seeing the teacher doing it, hearing about how it is done, she understood this and the massage I received from her, I realized that it healed me (Wagner, teacher of the massage course).

The technique I use is called Anmá, a very traditional and ancient Chinese technique. Therapeutic Massage is the one I most identify with and enjoy doing. However, I mix the techniques, I do three types of massage on one person. I can use a pumping technique which is part of the lymphatic, a "figure eight" on the back which is part of the relaxing massage and all the points are from the therapeutic. In therapeutic, I will just pick and squeeze the points, so I mix three types of massage into one. Most people expect a relaxing massage, so why not finish with a relaxing massage? I adapt a bit of one, a bit of the other to be complete, covering all aspects.

Because today I have another world view, I am identified with massage therapy. Being able to help others with therapeutic massage was decisive for me to choose my profession. Being of use to someone even in my current condition was decisive.

Now, I'll tell you about my work routine... I never like to leave things to the last minute, it makes me nervous. If a client suddenly shows up and my house is in disarray, I'll tell him I can't take care of him. Firstly, because I have a disability and it takes me longer to do things. As I like everything to be right so that I don't have any worries at the time of the massage, I have established a routine to ensure this. On the day I have a client, I wake up earlier, clean the whole house because I would never serve a client with a dirty house! Certainly, the client looks at the cleanliness of the environment, I myself would notice this when I was served and might not even comment on it with anyone, but I would notice it. Cleanliness says a lot about the person, for example, if I received a massage in a dirty house, on a dirty stretcher I would be disgusted, it is a set of things for a good massage. I tidy up the house and the massage environment, I remove any rugs or objects that do not belong to the environment, I prepare everything for the person, if it is cold, I warm the blanket, although it never stays warm until the person arrives (laughs). I take a shower, put on my work coat, and then I select the songs. I try not to always play the same songs for the client, I always try to vary. The client arrives, and I apply the massage (Conversations arising from the instrument A Day in the Life Of...).

I try to schedule only one person a day, unless it is an emergency, because I value the quality of care and also because of the situation of my arm. It is an arm that I cannot spend half an hour in the same position because when I try to change it will be numb and

painful, so I need to massage it and do exercises to make it come back. The act of doing the massage on a client demands a lot of effort from both arms, in one aspect it is good to stimulate it and not let it atrophy, but on the other hand, some repetitive and circular movements can cause pain, and so I avoid doing it with this arm, even so I can offer the client what she deserves.

I don't like to treat two clients in the same period because the quality I offered the first one, won't be possible for the second one. It's more than two hours of massage, it is always longer than that because I don't get hung up on the time, I don't mind going over ten minutes or half an hour of the established time. I avoid scheduling two clients on the same day or period because the quality of service would drop too much, I know I wouldn't make it because of the pain. I prefer not to do a bad job just to make more money, for a greed that today, for me, is not what really matters. Money is very important, I survive on it, but it is not the main thing for me, it is not the focus. Work helps me mentally, it helps me a lot!

With the pandemic, I was out of service for a long time and even with the relaxation it's not the same, the regular customers still haven't come back out of fear. For me, it was very difficult to deal with this, very difficult indeed! It was more because of the psychological part because I had just got married and moved to this house when the isolation began, and I stopped doing the massages. Working calms me down, I even think that the good it does for me is greater than for the person who receives it, in the sense that when I am applying the massage I can get out of my world. If the person speaks to me, I don't have that feeling, but if the client remains silent, it's just me and the body in all its grandeur. I go far away from there, I disconnect from external things, I am exploring a human being in

all its grandeur, unveiling every mystery. Because I am blind, if I am not totally connected with this human being, some things may go unnoticed like some points, so I need to be very attentive to what I am doing.

Of course, when it is already a known body it is easier, even with the person talking, I can perform the massage in all points, however, if the person talks a lot during the whole massage, it may be that they do not pay attention to what was performed and may wonder if I really did it. She may think it was too fast or something wasn't done, but in reality it's because she wasn't connected, feeling the effects, wasn't paying attention. I believe that being blind, I have the advantage of being more sensitive to my client's every point and need, to a much greater extent than a sighted person.

The main motivation for me to work is the mind. Work is something that helps me a lot. After the assault that I experienced, my focus became the fear that I feel, and it was difficult to detach myself from it. Work helps me to focus and think about something other than the aggression and allows me to stop thinking about what happened to me and even forget on the day that I am attending. The day I attend to a client, I have so many things to do that I don't think about it. Of course, if I am working, and I hear a neighbour banging the object which I was assaulted with, I will be distressed, but I know that it will pass because I will be focused on something else.

So, I come back to the point that when I am giving massages, I am helping someone. By helping myself at the same time, I am also being helpful. The period when my aunt was very ill, and I took care of her by giving baths, was very rewarding for me, first of all because I was doing it for someone I loved, but it would have also been if it

was for a stranger. I was being helpful to someone, I was the one doing it.

This aspect is still very difficult for me to deal with. Before, I was independent, I would go out and pay my own bills, solve my own problems, I didn't need help from anyone. Today I require someone, and unfortunately, I will do so for the rest of my life, on certain occasions, of course, only on those when I cannot accomplish something by myself.

But, at work performing the massages, it is different because there I am the one doing something for someone. I work for the money, to forget what happened to me, to help someone and to be the one doing something for you! It's not you and me doing it, it's just me. I don't need someone to give the massages, I'm doing it by myself, and I'm getting it done. Of course, sometimes I need Elis to check if everything in the room is alright, I need her to check if the sheets are perfectly clean, towels, details, but I'm the only one doing the main thing, me and only me!

# I have good relations with the clients, but a blind masseuse stirs up curiosity...

I have excellent relationships with my clients, I can't limit myself to just the moment of the massage without caring about the person after it's over. I can't help but send a message the next day asking if the person is better. The person may even think it's because I want them to come back, but it's really out of concern for them. My goal is to make the person feel good, to make them feel at least a little better about their pain, so I am being honest when I want to know about their well-being and wish them to feel better or to be relieved

from their pain. I am always honest with my clients and I don't make false promises.

Clients feel at ease with me, I have never noticed anyone being embarrassed to receive a massage. I think people don't feel so ashamed because I am blind, this makes the person not to feel embarrassed because they think "she can't see me". Of course, there are exceptions, there are people who believe that I can see a little, but even so, it is different for them, even if they think that I can see a little. This can be an advantage for me over other masseurs who see because no matter how much I touch them, I can't actually see them.

Do you think I know you? Do you know me? But I don't know you because I am blind. My blind friend once said to me, "Look, Beatriz, no matter how many years we have been friends, I don't know you and you don't know me!" No matter how much I touch the person, I will never see them, no matter how much I want to, I will never see them. In massage, blindness can end up helping, if I were shy, I would also go to a blind person to get a massage, without inhibition.

The fact that I am a blind masseuse also stirs up curiosity from some people, as they have already booked a massage just to ask about my story and because they knew I was blind. Honestly... I don't mind! If the person wants to see how it feels to be massaged by a blind person, I show them. Regina, for example, asked many questions about the assault and wanted to talk about things that I could not talk about at that moment because I was doing a massage and could not be so tense. If we talk about things that, I will laugh and relax all right, but to talk about a tragedy at the very moment when I am giving a massage is quite different.

As it was the first day exploring her body, I couldn't say much as I was getting to know her, however she kept asking. I would stop massaging when answering, and those two hours seemed like an eternity to me. I even went so far as to ask her to stop talking to me, so I could continue. To make matters worse, she brought a friend along as an escort who was also asking me questions. I did not have as much experience and security as I have today to ask for silence and explain that it was necessary, today I already know how to handle these situations.

This woman was one of the people who never came back, she came just out of curiosity. She would be a person that I would really like to come back because I would apply the massage the right way, without her talking, I would like to have the opportunity to show my work, but she didn't return. I know that in this specific case, my inexperience also hurt because I couldn't set the limit and show my work. Initially, I was ashamed and afraid of doing something wrong, now I have confidence, an appropriate place that allows me to close the door if there is a companion so that he does not interfere, and I can concentrate, but at first, I had none of this.

So, some clients approached me because they felt at ease with someone who cannot see their bodies, others out of curiosity either because of my story or to know what it is like to be massaged by a person with blindness. There are people who seek a blind masseuse because they believe she is a more intuitive and sensitive professional or has a special gift.

Beatriz is very much about spirituality. Massage therapists are called 'light angels of the earth' because of the time they dedicate to another person, because of their patience, because

of what they transmit to the other. Beatriz is not just a good professional but someone who transmits a light, she is an instructor, an agent of light, so she is above a mere masseur profession. The profession of a masseuse is just the vehicle for what she is transmitting, her training, her suffering, the result of a polished, broken diamond. She was even more broken than any other professional, materially speaking, she was even more broken. So, she is shining more than us. She has a lot to pass on to people (Wagner, teacher of the massage course).

Once, I received a phone call from a client who wanted to receive the massage precisely because she knew I was blind. As she was pregnant, I couldn't give this massage to a pregnant woman. She said she really wanted it because when she was living in São Paulo, she had received a massage from a blind person and would like to have it again. As I couldn't at the time, I ended up losing her contact and didn't look for her even after she had the baby. There is also another question, when it is a strange person, it is difficult for you to announce that you are blind, it is difficult, for fear of prejudice because prejudice exists.

There are also those who question my blindness. Many people have asked me during a massage, "are you really blind?" or "can you see a little bit?". It has already happened that a person calls to book a massage and I tell them I'm blind, usually the person doesn't show any prejudice, on the contrary, they answer in a very natural way, "Oh, OK, no problem" and I'm more anxious waiting for the answer than the person, for their reaction. Ivana is one of my oldest clients, but it took her a while to believe that I am, in fact, blind.

In the course, I passed on this attitude to the students, this concern with what the other is feeling, thinking, and I noticed that Beatriz, even though she wasn't blind since birth, but after her accident, even when her back was turned, when she noticed that I was coming, in silence, she already turned and positioned herself in my direction, she even said 'Wagner, you are already there'. And I would answer, 'Yes Beatriz, I am already here'. I noticed that wherever I walked, she would accompany me. I would walk from one side to the other observing everyone, she would accompany me with her head, looking for me to evaluate her. She developed this capacity to accompany someone with her face, even if the person is four or five metres away. I didn't know her before the course, but I believe that the activities developed in the course contributed somehow to Beatriz's evolution, and this caught my attention (Wagner, massage teacher).

I don't even know what to say, or the other blind people are very limited, or I don't know what it is. I take it as a compliment and I don't get offended, by the way, it is very difficult for me to get offended by something related to my disability, unless in a discussion you call me blind with an air of cursing, then I feel like tearing your eyes out too, but otherwise, I take it easy. Helena, my friend, cannot be called blind even in jokes, she says she is not blind, she is handicapped. I think the opposite, I accept being blind, I don't like being deficient, it seems to me something so limited. I prefer to be blind, I am blind! It's not a lie!

However, regardless of the reasons that bring each client here, what I know is that I attend each one with the same satisfaction and dedication. I have never felt any kind of discrimination, what I

perceive is the curiosity of others, but not discrimination. I feel that I am the one who discriminates when I think I have not done well, but not that the other person thinks or says the same.

I am perfectionist and demanding with my work, not just to prove that because I am blind I am capable, but because of my own personality of wanting things to be right. However, I know that it helps to change the concept that some people have about the blind person. Of course, most people have an opinion and don't allow themselves to look at the disabled differently. But, some change the concept of "Wow, she's blind, and yet, she works, she's hard-working, she's capable". This opens another perspective about the disabled, it breaks the idea that the disabled person is useless!

After I started giving massages I changed a lot, not that I do a lot of them because I do restrict myself in the services, because of the disability, because of the difficulty with my arm, because of the prejudice regarding my sexual orientation, there are several obstacles that prevent me from doing even more, but I still choose to work and overcome my limits. I choose to work because when I give massages, apply some new procedure that I learn, finish and ask how the client is feeling, and I hear what Ivana told me that she was feeling well, that she feels like a diva after the massage, an enormous joy invades me and there is no money at this time that can overcome it.

Sometimes what I earn doesn't cover the expenses I end up having with the tools I use, but nobody needs to know. If I didn't work, things could be much worse, work really builds me up. We all have to work, everyone should have the right to work because that would help a lot in overcoming. Even working inside, not leaving the house and interacting with few people, it is still rewarding because I do not feel totally exposed to the stigma of society.

Work for me is a way for me to face my disability. It is the way I found to overcome my own limits, I can do it, I did it! I do not pretend that it will change people's conception of me, nor do I do it to prove anything to others, only to change my own conception of myself and prove to myself that I can do it. I could be quiet at home receiving my help, I don't need to be giving massages, I could be protected in my own little world, but I feel the massage is more beneficial for me than for those who receive it because it helps me to take care of my mind.

Work has changed my mind, it's good for me mentally. I always liked to work, so that didn't change. It does me good to know that I am cleaning the house, getting ready because I am going to work. Work has always been a part of me, to know that I can work despite being blind is much better! I don't do it to prove anything to anyone else, but to feel good about myself, although I believe that it will have an impact on others...

My profession represents much more than a salary, it represents my autonomy, something that I do without needing someone else to do it for me. At that moment I don't need anyone else, I just need me. I may need someone to check if something is well cleaned or well positioned, details that help me, of course, but to apply the massage, I don't need anyone else, just myself. This helps me to grow, to strengthen myself, to grow even spiritually. In short, my work means strength, growth, autonomy, dedication, passion, and love for others!

## All disabled professionals cut from the same cloth...

When I'm giving massages, if I'm stressed, that's what relieves me. When I know that the person arrived in pain and left feeling better, it does me good. Today I wasn't supposed to give any massages, but Ivana sent me a message saying she was in pain, feeling unwell and asked if I could help her. Immediately I said yes, I woke up early, arranged everything for her visit. When I'm massaging her, I know it will ease her pain, I feel good helping her. I feel good!

I avoid working with men, it is more difficult, there is a whole context involved. Among other reasons, because of men's sensitivity, you need to be more careful, you can touch them, and they interpret it differently. A man's vision of a masseuse is very different to that of a woman. If it is an acquaintance, the husband of a friend, I will do it, but if a stranger asks me if I do a massage, I answer no because I don't know what he is like, there are many naughty people who come with other intentions.

I know blind masseurs who have not taken the course and advertise that they do massage, but offer another type of service, an erotic massage. Some men seek this type of massage because they do not differentiate the professional who is trained from the one who is not, they generalise. There are various types of massages, and it has happened to me that a man has asked me if I do a Thai massage, in which the supposed masseuse rubs herself against the man and touches certain points. There are many things involved, I explain very well the type of massage I perform so that there are no doubts. That and avoiding attending men and sometimes even women, depending on who it is.

I met a blind person in the association who adopted this attitude and, even without any course and knowledge on the subject, offers another type of massage. This makes me very angry because the client is in pain and ends up being cheated, it's an abuse, a theft, the person is in pain and trusting the professional who doesn't even have the knowledge and training for this. Although most of this person's clients are men, and I can imagine why... they seek exactly the eroticism and sensuality that she offers as a massage.

The fact that the person I mentioned performs such massages without a course that would qualify her and with erotic connotation hurts me a lot because people tend to put all deficient professionals in the same package. She didn't want to take the one-year course I took in order to become certified, she just went to a masseuse, got a massage and went out applying it to people as if she were a professional.

For this reason, I need to be very careful about who is the man who would come to my house to get the massage, sometimes it is better to say I am a massage therapist than a masseuse because massage encompasses things that people end up confusing. Depending on the person I'm talking to, I introduce myself as a massage therapist, so they don't mistake my work for erotic elements usually associated with the word "massage". This week, a man with whom I have had a relationship in the past called saying he wanted to get a massage, but I can tell from his tone of voice that this was not exactly what he wanted. How do I get out of this situation? I replied that I didn't have an opening, but that I would let him know when it came up. However, I won't get back to him because I know he wouldn't be there for my work. That is why I prefer to attend women or men who

are married to friends of mine because it requires a certain amount of caution when it comes to men.

For us blind people, it is already very difficult to find work and courses because we are considered incapable, and I still come across a person who claims to be a masseur when in fact he isn't, he doesn't have any training and still puts a sensual connotation on what he does. What happens to my work? It is devalued! Besides increasing the prejudice against us. Most of the men in the association seek her massages, and this distressed me because I knew she was not a professional and was contributing to misconceptions about real professionals. She knew how to do common movements that any person does in their daily life, without technique and no knowledge about the body, the points, results, diseases.

I've had people come here to get a massage just out of curiosity for different reasons, but the reason that really bothers me is about the seriousness of my work. I'm not better than anyone, there are people better than me, and whatnot, but, if I'm giving someone a massage, that person can be sure that I'm doing it with professionalism, respect, and love for the profession, which nowadays is difficult, people value greed or charlatanism.

#### I've been on the other side...

This week, something happened that made me very sad. My godmother had a gallstone and had to go to the Emergency Room alone. When she told me that she was there in pain and alone, I asked her why she hadn't asked me to go with her. The next day she would return for her exams and I offered to accompany her, and she asked me what I was going for if it wouldn't do any good. Hearing this was

like feeling a knife stabbing my chest. I replied that my company would at least be good enough to call the fireman for help, and she answered that she could do it herself. I cried a lot, I was sad, and I thought it sucked to be blind. Some time ago, I offered to be a companion in a hospital room when she had surgery, and she answered that she could not have a companion, but soon after she posted on her social network thanks to the person who accompanied her...

Blimey! A blind friend of mine spent a whole afternoon in hospital and I accompanied him, I helped him in everything I could, I am useful for something, I was very unhappy with her answer. People limit the blind a lot. There are situations in which I myself know that I can get in the way and prefer not to participate. If it's a situation that demands haste and agility, I refuse to participate because I know I can't, and I might get in the way. However, there are situations in which I can help in some way, such as keeping her company, chatting, picking something up, but if that is what my godmother thinks, I respect it, I don't want to have to listen to it any more, I don't offer myself for anything else in relation to her because if I am compared to another companion because of my sight, it is certain that I will be at a disadvantage.

It's very difficult for me to feel at a disadvantage with someone because I always try to keep up with everything they're doing, but I've had moments when I felt at a disadvantage. The professional who is making a piece of furniture planned for my living room, whenever he comes to discuss the details of the furniture or the budget, he asks to speak to Elis and if it's not possible, he simply doesn't deal with me because he considers me incapable of solving them. He came on Elis' day off, brought the specimens and dealt with

her. However, the part concerning the financial budget we agreed would be dealt with me. Even so, when he handed me the paper with the figures, he asked Elis to call him, totally doubting my capacity. Elis pointed out that she would not call because this would be resolved with me, but the professional never calls me and always the person who has the vision, this annoys me, but I don't say anything. This puts me at a disadvantage, I get irritated.

In a shop, I am always ignored as if I am not there or as if Elis is my nanny. People believe that Elis works for me, that she is my carer. Once, when I went to a checkout in a supermarket, the girl asked if she wasn't working that day because she wasn't with me. People constantly mention how well looked after I am by her. Gee, do they think I do nothing? One woman in church even told me that she takes good care of me because I am always "clean". There are people who ask me, "Do you shower by yourself? Can you take your shower by yourself?". I don't know that if I was a sighted person, I would also think this way, I don't know, I am on the other side of the story now, but how could I not be able to take a shower? Since I can be harsh in my answers, I prefer to be quiet, but I feel very irritated by the situation.

And if in any situation like the ones I mentioned, I really got angry and expressed or told these people that I am not useless, that I wash and iron my own clothes, people would say it's because I'm an "rude blind person" or that I'm "stressed about being blind". I know people infer this because I have been on the other side and heard what they say about people with disabilities. When I worked in the factory I had two deaf employees. They would drag the big objects that made a loud noise and almost deafened us too. I would gesture for them to stop dragging and hearing people would criticise me, saying that it

was because of their disability, that it made them "very angry people". They would say the same thing about me if I complained or explained myself and actually, they are kind of right because we no longer have patience with everyone who doesn't understand us, which happens with most people, and we end up becoming more sensitive. Then they would say, "the blind person is so angry!".

I can foresee and imagine the person looking at me with pity or incredulity, or even exchanging glances with others on me. I can imagine these situations because I have witnessed them when I was psychic. So, I prefer not to argue with people, only if I am on a very angry day.

In certain situations, I notice that they stop to look at me. Sometimes I'm walking with my sister and just ahead there are two people talking, in many of these times they don't give me permission to pass, they just don't move to the side, so I have to go out to the street to deviate or ask permission. Juliana gets annoyed and says to the person, "can you please let us pass?" as if to say, "can't you see that she is disabled?". Sometimes it is necessary to touch the person with the cane and still, they don't give let you pass, they bump into me and I know that the person can see me, but they don't bother to make room. I get very aggravated, not because they are bumping into me, but because they are bumping into a disabled person! I keep thinking, "What would it hurt you to take a step back so that a disabled person, a wheelchair user or an elderly person can pass?". Stop and pay attention to the streets around you, what happens to the disabled. People don't care, they are always rushing around, talking on their mobile, and they bump into me several times, all the time, they have already knocked over my cane countless times because of these bumps.

I watched a news report in which the owner of a department store was criticising the fact that he had to put a tactile floor on the pavement of his shop because it would change the pattern of the façade. He suggested that whoever was so concerned about the tactile floor should put it in. Blind people should unite so that none would enter and shop in the shop of a person like this! People don't care about the disabled, society doesn't care about this. People never believe that they can become a disabled person, just as I did not believe it. When could I have imagined that I would become blind at twenty-eight? I would never have imagined it. We don't have that preparation, thinking, and we don't look at these things.

At the hospital in São Paulo, which is very big, there is a tactile floor and, besides that, there are support bars. Sometimes I try to walk independently, but people lean on the support bars and stay there talking, preventing the passage of those who depend on that to walk. In other words, besides the structural barrier, when this is remedied, we have to deal with the barrier of people's disrespectful attitude towards these situations.

On the occasions when two or more people are talking, I hear from the sound that they are looking back to watch me after I have passed them. I realise that they have turned towards me. I feel I am completely ignored and invisible when it relates to respecting my needs and the opposite happens, when it relates to labels I am seen, watched and exposed, I have become the target of comments, pity, curiosity, criticism, comparisons, a reference point, almost always a negative thing.

### I have become a reference point

The problem with being blind is that there is a lot of comparison. If another blind person walks alone, does this or that, has another ability that I don't have, then what happens, the other people who see us together start questioning "Wow, Beatriz, but that blind friend of yours can do something like that, and you can't?" There are so many comparisons. "Wow, but that blind woman teaches classes, gives lectures, and you don't?". There is a lot of comparison as if one should be equal to the other. Each one of us has our own gift, whether we are blind or not.

There is still a lot of prejudice. Even the blind themselves end up being prejudiced against themselves, but this is due to society being that way. For example, if you watch television shows, how many times have you seen blind people participating in them? The other day I saw on a television programme the story of a blind hairdresser. I was interested in the story, and they started saying that the person had been blind since a certain date, etc. I stopped what I was doing to watch it and, thinking it was really cool, I began to imagine how she could achieve such a thing and that I couldn't even imagine it. When I say a blind person, I don't mean a person with low vision.

I followed the programme to the end and found out that she completely lost her sight in one of her eyes, but still had a percentage in the other. In other words, she was not blind. At that moment I stood up feeling angry, I wanted to write to the presenter of the show and explain to him what it is to be blind. These situations make me angry because people generalise and believe that the individual is really totally blind, so I should also do what they do. People label,

they put everyone in one category as if we were all the same. It's the category of the disabled, with no differentiation between those with blindness and those with low vision. And based on that, they compare you, if a wheelchair user can get around alone in his wheelchair, why can't the other one?

The blind are not a united group. They cannot unite to fight for something for the benefit of all. They lack a strong resolve and are individualists, each one tries to do alone that which will bring only their own benefit. They don't fight for their rights. Each one for themselves. I voted for that wheelchair-bound councillor, and she does fight for us because if it wasn't for her, we would lose many rights. But I think it's not easy for her to be alone in that environment. People don't care, they won't put a ramp so that only she can go up. They don't care about the disabled because there's only one of them.

Today, I am sure that my disability has made me the target of comparison and a point of reference "Do you know Beatriz, the one who is blind?" However, I don't mind that, but there are people who treat that with disrespect. There is a big difference between you joking and discriminating, treating with inferiority, saying "That little blind girl over there". There is a difference! Most of the time, I take it as a joke because if I get angry with everything, then there would be too many things for me to stress about, and I would be considered ignorant in everything. Of course, it also depends a lot on the person who jokes. Blind people with blind people, we understand each other because we are blind, we are at the same level, on the same level. When I'm with my blind friends, I feel like myself. We all have the same difficulties, we all bump into each other, we all knock into each other, the stories are ours, the difficulties are also ours, so it is very

different from when I am with my sighted friends. If you put a bunch of blind people where we are... wow... we talk and talk! We joke with each other, "Give me your hand, it's like you're blind or something!" (LAUGHS)

Now if another sighted person goes and jokes saying "Oh, you blind person!", they will be offending me and I will want to offend them back! Usually, this doesn't happen, only with the people in my family at home, strangers have never done it. Except for one time when one of Elis' ex-girlfriends, who already didn't like me before I became blind, heard that Elis and I got back together and said, "Are you going to dump me to be with that blind girl!?".

## I have a story beyond blindness...

The world is not for people with disabilities, people talk about inclusion, but I am against this way of including by excluding. If I had been blind since I was a child, I would not want my mother to put me to study among people who can see. I would prefer to study in a school where everyone was blind. I would like to... because there is a lot of difference. No matter how much they tell me that there is inclusion, that they respect my needs, I am not totally included. There are many barriers, people look at me differently. I end up feeling that I am harming others, that I am bothering someone. I do bother myself! Since I don't want to bother anyone, I withdraw... I am not in favour of inclusion. I do not want to live among people with whom I do not feel comfortable, without being able to be myself. In this so-called inclusion "you have to live together, you have to, you have to", everything is an imposition.

Ask any blind person who went to college or studied among sighted people, I am sure of it, ask them if it was easy. It is very difficult! Imagine everyone can see, you being the only one who can't, having a hard time keeping up, trying to do something you know you are capable of doing, but that you need someone else to help you, it is very difficult. So, I prefer to be there in my little world. People are not aware of the necessary support to include the person with disability.

For starters, people don't even have the notion of how to guide a blind person, which is the beginning of everything. The women who work in the association, for example, do not know how to guide us even though that's their job! They pull us by the arm when the correct way is for me to lean on the person. You do not need to touch the blind person, you can ask if you can help them, and they will hold your arm, it is they who hold you and not the other way around. People mistakenly hold the blind person by the arm and the blind person cannot walk! I definitely become really blind, I can't see anything, I can't even get out of the place. The ideal is that the blind person holds you and not the opposite. If you are going to help a blind person to sit down, just take him in front of the chair and tell him that there is the chair and let him touch the chair and sit down himself. Instead, people say "Move away, move away, keep moving away" pushing you with their hands.

I easily lose my plot in these situations, and then I regret it, I know that the person was trying to help, however, the excess of care is irritating! I don't know if it is different for people who were born blind because it is another perspective, but as I used to have my freedom before, my independence, I used to do my own thing, it is difficult to be completely dependent on others. It is difficult to accept

that they prepare food for me, that they do everything for me, it is difficult. There are times when I need help, but at other times I can do things by myself. I have already sewn with a needle by myself, I just needed someone to pass me the thread, and I was able to sew by myself. I will do it. I can do it, I can!

I take a crochet course where everyone is sighted, and I'm the only one who is blind. I'm taking this course for a year now, of course, I can't do everything they do, but there is a Russian stitch that no one has managed to do, and I managed to do it. At the same time that it is enjoyable to accomplish something, there is also the other side. For example, I know my stitches are not good, I know I made some mistakes, but people stare and exclaim "congratulations, it's beautiful!", and show it to everyone, they comment with admiration and I stare at the scene and think "Wow, it was not that big a deal!".

The first round rug I made gave me a nervous, headache, and I gave up doing it, I said I couldn't do it. I learned the stitch of the oval rug and I recognised that it turned out beautifully. When someone else does it and receives congratulations, I realise that it is another tone of voice and I wish they would use the same tone with me, without so much astonishment, without exaggerated admiration.

But with me, it is always different, people come and say that I am a warrior and that they love to see me, someone's husband said that I am incredible, etc., but I don't see that! It is a strange thing, suddenly I have become an object of inspiration for others. It's strange, it seems that I am no longer me. I have to be dressed up all the time because I'm more visible now, I have to have etiquette so that people don't think I'm poor or uneducated because I'm blind. People may point at me and say "oh, poor thing, she's blind, leave her alone", as if it was OK that I knock over food or eat with my hands

because I'm blind. The poor blind person has no etiquette, they don't need it! I do acknowledge that there are blind people who are, in fact, like that, perhaps for lack of opportunity to learn, for not having been taught, for the education they received, and they have more social difficulties. People tend to generalise, they see a blind person who does not know how to behave at the table, I am blind too, so they think that I will be just like them, even when it comes to eating, having a cup of coffee, we will be the same in everything. People think that if they put several blind people at the table, they will all be the same.

The blind person is targeted, so if I go out somewhere people will look at me because I am blind, because I am with a woman, there is a whole context, although many people think that Elis is my carer and not my partner. They ask "Are you the one who takes care of her?" or if I go to a certain shop to buy something and the person addresses her as if I were deaf too, as if I had no voice. Elis passes the question to me and I answer, but I get aggravated, this happens to all blind people, people don't address us, they address the person next to us. I feel useless. After a while, the person ends up talking to me, but at first, they never address me. Since Elis knows me very well and knows that this irritates me, she herself asks the person to address me directly or even leaves me alone when I am buying some clothes, for example, she lets me sort it out with the saleswoman so that she is not asked anything.

Sometimes I'm on display like an object in a shop window, sometimes I'm invisible, they don't address me. There are people who pass by me on the street and don't say hello, and that hurts me a lot. There are some who pass by me on the street and shout "*Hi, Beatriz*", they don't identify themselves, often I don't know who it is, but I

answer their greeting, happy for the fact that they were considerate enough to greet me, for being polite to me.

I wish people would see me as a normal person, that they would greet me when they see me in the street, that they would continue with the same vision that they had of me before the accident. This is because I have a whole life path, a whole history of not being blind, I have a personality, a history of what I was before the blindness and people don't understand this. Who was that Beatriz? Today there is only the Beatriz who is blind, as if they erased my past. Of course, even for me, today there is another Beatriz, only in certain situations and not all the time, because I still have within me the Beatriz from before and I will carry her with me for the rest of my life. These are good moments that I went through, and they will be eternal, there is no way I can simply discard them. But society sees me as that "poor thing".

Of course, regardless of disability, if there is a situation in which you need help, if you are lost, going through a difficult period, without being able to do something, and they offer help... then it is a totally different situation, I will want help, for me, it will be a glory to be helped in a difficult moment. But, it is not all the time that they need to see me as "Oh, that poor thing", I can manage by myself and for society I am incapable. Even if I know how to do something, I am seen as incapable!

I don't know if we disabled people... if we try to fit into society, try to be present, try to make society look at us as a normal person, look at us with normality, but deep down, deep down, I know that it is not like that, people look and imagine that certain things will always be impossible for me because of my blindness. In certain situations I want to do certain things, but I am stopped. I know I

won't be able to accomplish certain things if I don't try, but people don't allow me to do anything. I feel limited and this is where time goes by, time goes by... soon I'll grow old... and that's it!

# People think that besides not seeing, we don't hear, speak or think...

This week something happened that upset me, although it's something that always happens, it still annoys me. I went to buy essential oils in an exoteric products shop. I asked a saleswoman for what I wanted while Elis looked at some things. I wanted to choose oils, scents and also therapeutic stones to use during massages. Elis started asking the saleswoman about the stones and the girl answered. I asked her if she had rose oil, and she answered briefly, turned to Elis again and said that she had studied with me. I heard her saying that she studied with me, and I turned to her, asking her her name. I was surprised because she was a friend who was around me a lot and never greeted me at the shop she had been working at for two years. I asked her why she never spoke to me in the shop, and she replied that she never attended to me, however, every time I was in the shop, there were no other customers because it was a very quiet shop, meaning that she could at least say hello to me. I always lingered in the shop, enchanted with the bells and other objects, and she was there, but never greeted me. What annoys me the most is that she didn't tell me that she studied with me, she told Elis, I was right there beside her, and she didn't address me and that's one of the things that happens the most. We blind people think that besides being blind we are deaf, dumb, we are sure of this! Even in the supermarket, people talk to whoever is next to me, even if I'm checking the product at the checkout, they don't address me. Sometimes I could or should be able to answer, or sometimes I am giving the money to pay, and the change is not given back to me, but to the person next to me.

As Elis knows this is one of the things that irritates me the most, she tells the person that they can address me or give me back the change. I always called this prejudice, but I see that it is the stigma, it is the little everyday things that most of us with disabilities suffer. I think the blind in relation to other disabilities suffer even more when it comes to being ignored in shops, in supermarkets and everywhere, it's always "What does she need?" and never "What do you need?". It is I who need the object, I who should answer.

There was the time when I went to a shop to buy a shoe for my father. Because of the pandemic, I couldn't enter the shop. The girl was showing the shoe to Elis through the glass display case, but I couldn't see it. I said, "Miss, I need to see it before I buy it". The saleswoman answered that Elis was already looking! As if that were enough. But what about me? I answered, "Miss, that's for me, I'm the one who's going to buy it". Elis helped: "She needs to see it because she is the one who is going to buy it". Only after Elis' intervention did she allow me to touch the shoes. People see me as incapable of deciding anything, like what I will buy, wear, eat, dress, the way I walk, I am considered incapable of everything. I would like to understand why people believe that we are incapable of achieving anything. We do have limitations, but we can achieve many things. We can do it!

Like this friend of mine from school who didn't greet me, I remember her, we hung out a lot. After I went blind, I looked for her on *Facebook*, but she didn't have me anymore, and I don't know what happened. She said it could be that her husband had unfriended me

by mistake or whatever... these are some little things I don't understand.

Regarding disability, I always feel the stigma in shops or when I have to solve things and make choices, like the panel in my living room where the professional was showing the colours exclusively to Elis and when I approached him to know the colour options he didn't address me either. In order for this to happen, Elis had to leave the room, leaving me alone with him. Back to the story of the stones I wanted for massage, I'm the one who works with them, but the saleswoman wanted to show them only to Elis, even if I approached, she didn't address me. My reaction to these attitudes is to withdraw, I can't talk to the person, I remain serious and quiet. Elis notices and moves away so that the person has no alternative but to attend to me.

Many times Elis says, "Show her, you can show her, let her take it, she can decide", most of the time that's what happens. People need Elis' approval, she is my voice, I don't have a voice as if I were some poor thing and couldn't manage on my own. I can only imagine what happens to blind people who walk alone or go to the supermarket alone... buy clothes alone...

There are many stigmas and prejudices, people think we are incapable of anything, that besides not seeing, we blind people also do not hear, speak or think. Many times, when clients come to my place for a massage, they are surprised and ask "Wow, are you the one who cleans the house? Can you do it? Wow, that's so lovely... how do you do it?". I feel like answering that it's obvious that I can do it, it seems obvious, but I just answer "We learn, and we do it".

The questions are so absurd that I feel like laughing, like the one about whether I can shower by myself. I try not to show my frustration to the person, but inside me, I am extremely annoyed. If

I could react the way I wanted to, spontaneously, I think I would say things like "Look, I exist, I am here, and you can talk to me directly". But, I don't say those things so that the person doesn't get hurt. I would rather be hurt than hurt others.

Besides that, the disabled person is already a little more aggravated and irritated than the person without a disability. I had this perception before, when I could see and saw the attitudes of two deaf people at my work and heard people commenting that it was because they were disabled. Today, I go through that myself because we need a lot of things to defend ourselves in front of people who limit us because of the disability, because of the things we have to explain, demystify all the time and this becomes tiresome. If I acted the way I feel irritated, they would say the same about me, that is, that I am nervous because of my disability, "That blind person is angry", they would not see me any other way, everything good I did would end, and they would only see the disability, they would only pay attention to the detail of what I did wrong, the ignorance, the nervousness, the rest would end.

Of course, I often feel like reacting without thinking too much about what to say, like treating them with the same disrespect with which I feel treated. When I go to buy something in a shop and the salesperson doesn't address me, I withdraw and get irritated, but I would like to say that, please address me, I can understand, listen and speak. When friends meet me in the street and do not say hello, I get very hurt because I have always said hello to everyone in the street, people even joke that I should be a councillor (laughs), but my wish would be to go back and say clearly to the person "Hello, what's up? You did not see me, but I saw you" or accidentally bump into my cane and say that I did not see it (laughs).

When the carpenter prefers to deal with Elis only, I try to explain that he can talk to me, that he can send the budget on my *WhatsApp*, I try to negotiate and convince the person to talk to me, but it doesn't always work, and the person insists on talking only to Elis. My desire is to explicitly say "You can talk to me because I understand, I can understand a damn colour name". When they are new names of colours and strange ones, I don't really understand, but if you tell me what it resembles I can identify it. Nowadays, with the changes, clothes, for example, they speak names of some pieces that I didn't know, but it's enough to explain to me what it is.

When they think that all blind people are the same and should do the same thing, have the same abilities and difficulties, I just apologise and say that I can't do it, when my real desire is to respond aggressively to the person. At the beginning of the disability, I could not put butter on bread. I still couldn't see with my ears and hands, being blind in all senses. People dragged me wherever and however they wanted, I couldn't do anything yet. Imagine a cousin you only saw as a child changing your nappy? Very embarrassing. Especially me, who didn't even change in front of my sisters. Comparison is something that annoys me a lot because no person is equal or has the same abilities as the other, why should the handicapped be? Clara reads in Braille and my aunt always praised her to me, giving me a nudge because I couldn't learn Braille. Elisângela, who had been blind for longer, thought it was absurd that I couldn't spread the butter on my bread and told my father that it was shameful that I couldn't do it. Today, I feel like calling her and telling her in a provocative tone that I can wash clothes and she can't. These situations annoy me. I feel like saying, "We are not the same, I can't do this!".

However, if I acted and responded that way in those situations and to all the people who compare, label, limit and discriminate, the focus would not leave the disability, they would sentence that the attitudes or words are because of my disability and not their behaviour. So, I prefer doing to talking, in the episode of the girl from the shop, for example, when I talked to her and chose what I wanted, at the end of the service I had already added her on *Facebook*, talked a lot, and she saw that I am capable. If I fought, she would just think I was nervous, she would never attend to me again, she would call me revolted because I am blind or revolted because I am a woman who has been assaulted. These are things that I have to be aware of because otherwise I will be called ignorant and nervous. This prejudice always happens, not only with salespeople, friends, but also with family members themselves.

I was walking with Elis around the market and I passed the Camelódromo (large open thrift shops), I have cousins who work there. I went by my cousin who had her back to me and Elis warned me. I said, "Hi, Larissa" and she didn't answer. I said she must be busy, but Elis told me she wasn't doing anything. I passed by my cousin, who was sitting looking at me and didn't greet me. Because I am blind, I believe they think "We don't need to greet her because she can't see". That is what happens most of the time, and I have nothing to say to these people. This doesn't just happen to me, but my blind friends report the same situations, and this for me is a stigma.

I was talking to someone who said, "The other day I saw you at the supermarket". I asked him why he didn't say hello, and he replied, "I was busy, I was in a hurry", it's always the same excuses even if they pass me by. I don't know if they think my intellect has been affected or that I have become untouchable... I believe that

some people do not know how to act in front of all that has happened to me and the disability, but not all of them, many ignore me out of pure prejudice. I myself have already had no reaction in face of a friend who was bedridden and suffering a lot, but they are different cases, I walk, talk, work and greet them, but they prefer to ignore me. The curious thing is that soon after the assault, when I was still in hospital, what I received most were visits from people who wanted to see what had happened to me, it wasn't out of concern, it was curiosity, now that I'm well, they don't care anymore.

## Avoiding confrontation is a way to escape the stigma...

Avoiding confrontation is a way of escaping stigma. I lost my sight, but people associate me with other disabilities like intellectual, deafness, physical, and they assume that I can't talk, so I talk a lot (laughs). I think there are people who manage to face the stigma on us in a more direct way, confronting, debating, but I avoid confrontation most of the time, even though I am angry by nature, I prefer to swallow it rather than confront it because the consequence is that people would see me in a different way, as a grumpy and fussy person, rarely would they notice firmness, conviction or that I was changing a situation, most would label me as a fussy and angry blind person.

They wouldn't recognise that I would be demanding my rights and would just label me ignorant. Although we almost don't use those rights because it's so difficult to use them, so difficult to get a ramp, etc. To be able to buy a car, for example, you have to get a certificate from the doctor, go to the DER ("Departamento de Estradas de Rodagem" or Department of Highways) and get another

form to fill in. Besides this form, you have to go to the doctor to get another one in which you go through a medical board in which all of them must authorise you to buy because of the disability. This is paid, it is not simply to go and go through all the bureaucracy, it is necessary to pay to do this, the value is high, around R\$ 700,00. Some time ago, I got informed and found out that it is necessary to go to another city because there is no such service in our city. Besides other numerous requirements to be fulfilled, documents and papers to be delivered, reports and consultations. My report specifically needs to be from São Paulo, and it is even more bureaucratic, even though my disability is visible. It is all so bureaucratic that it seems to be on purpose so that the person with disability gives up their rights.

Prejudice today encompasses black people, the poor, but the disabled are the most stigmatised in my opinion, they are already seen as someone who is incapable and who will generate work for other people. In my point of view, inclusion should not exist, at school for example. It should be blind people with their equals, separated, so that they learn according to their needs, disabled people with disabled people because we would feel much better and learn much better than when mixed with people who do not have disabilities and do not know how to deal with inclusion. There is prejudice from colleagues, from teachers, unpreparedness.

If parents do not teach their young children to deal with the disability of others, they will go to school and isolate the disabled person, they will not call them to play, and who will suffer from this? Now, if the blind child is in an environment with blind children who understand them, they will interact, play because they are all the same. When my blind friends come to my house, there is no prejudice, and we end up being ourselves, if we drop something on

the floor, we laugh, accept it and face it naturally. If I do the same thing, as has happened in the presence of psychics in a restaurant, or bump into something, everyone looks at me, I feel people looking at me as if I had done something terrible. I have to be careful and watch out when I eat, when I cut the food so that I don't fall over, so I ask Elis to cut the pizza or the meat so that I don't fall over and feel embarrassed, to avoid the prejudiced look.

If you leave me alone in a UBS ("Unidade Básica de Saúde" or Basic Health Unit) or in a snack bar, nobody will come to talk to me, unless it's the waiter asking if I want something. In the past, when I was waiting to be attended to in a UBS, what I did most of all was talk to people, I loved to chat. Now... I enter and leave quietly, I am invisible in certain situations and in others, like when I drop something, all eyes are on me or when I arrive somewhere and Elis tells me that everyone is looking at us. I try to take it in a good mood and say that they think I am pretty and that is why they are looking at us, but I know that they are looking because I am with a woman, and I am blind. I have a double stigma.

## It's my way of avoiding stigma...

I really don't know if people judge me incapable of doing my job because of my disability, I don't know because they will never tell me directly what they think. How can I know that people don't come to me with the intention of seeing if I will really succeed? That is an answer I don't have. I believe that it has already happened like those who came once and didn't come back, maybe they came just out of curiosity, asking themselves "Can she really do it?". That's what I believe in.

At first, I was intrigued, I thought, "How is a visually impaired person going to give massages?" I went there, and she told me that she had already done the course before she lost her sight. She asked me if I had any specific pain and I answered that I had fibromyalgia and that all my muscles hurt, I just said that. The first time I got the massage from her, I was already 0,amazed, I don't know if it was because she couldn't see, she developed more contact with her hands.

What I admire most about Beatriz as a professional is her courage. Very brave! I believe she has already suffered prejudice at work for being blind. She never told me about it, but I believe she has. When I mention that my masseuse is visually impaired, people are amazed and ask me, "How?" I explain that because she is visually impaired, she has developed a lot of touch, but people doubt it. That is why I say, she is a very brave person, I admire her very much, as a person and even more as a professional. She was very intelligent, she adapted the massage to my case, studying my disease, not even trained professionals do that, they don't have time to attend according to the needs of each patient, there is only one massage for all, even with her lack of vision, she studied and adapted. Today, she knows all the points of fibromyalgia. But, people don't believe this (Ivana, Beatriz's client).

I don't think I am visibly or even more stigmatised because of my behaviour. The fact that I have certain abilities such as looking in the direction of those who talk to me, walking with agility, among other things, makes the person end up looking at me in a different way as if I were really seeing. To this day, Ivana has her doubts that I can't see anything. I asked for her arm because I couldn't find the door and she, surprised with my difficulty, answered that I was

accompanying her so well, talking and looking at her face, that she even forgot my condition. I think that if I started to see people without glasses they would be more convinced, they would find it strange because then they would have something visible that would prove my disability.

If I took my glasses off during the massage, perhaps people would treat me with more prejudice, but I wouldn't do that, firstly because I don't take my glasses off for everyone, I have many friends who have never seen me without my glasses. I don't take them off because they would see me the way I am today. I don't want people to see me the way I am today, I don't like people to see me as disabled, I like people to see me simply as the Beatriz that I am, with the defects and qualities, but not as disabled, that's something I don't like. I don't like the pity, to be pitied, to be told "Oh, such a shame".

I get frustrated at the thought that if I were without sunglasses, the person would be looking at me with a look of pity, fake sympathy, while I would talk naturally without being aware of that look and without being able to look at them with an air of protest so that they would not look at me with pity. I don't want that in my life. I don't want people to look at me with pity because it is not really necessary. When I see someone on the street in need, I feel sorry for them, a disabled person lying on the pavement, I feel sorry for them as a human being, but I am not in that situation, I am not sick, bedridden or comatose, I do not need pity.

Wearing glasses is a strategy, an escape to protect myself from pity. I don't go without glasses. Most of my blind friends don't wear glasses. They are different from me, they don't need to wear them because their eyes are there, they were not torn out like in my case, it is another view of a face. I cannot compare myself to these people,

saying that I am disabled like them, so I will also be without glasses, I need my own strategies. When I did a course on self make-up for the blind, they were all without glasses, I didn't let them take photos of me. All without glasses, learning to apply pencil to the eyes, I can no longer... I have even one eye and the one that is left only remains closed. So, I am very careful with photos because I am afraid that people will put them on the internet because the curiosity is great, I am careful. I try to go out dressed in my style, the way I like it – clean, tidy, I try. Of course, sometimes it happens like recently, I went to the psychologist with my clothes dirty with coffee powder (laughs), that made me angry. But, it's blindness... damn, being blind is a drug! (laughs).

But I also wear the glasses so that people are not frightened by my appearance, there's that too, but it is not the main reason. My strategies to protect myself from the stigma are to wear glasses, to always be well groomed, to leave the house tidy and clean in order to receive clients, to have certain expected behaviours such as looking in the direction of those who speak to me and not to be harsh with words even in the face of the most absurd questions. Sometimes I think I worry more about the person than I really should, and this is already part of my personality even before the disability. I am not overly careful with myself. But I do care about my appearance, I am more vain today than I was before the disability. I think it is important what others see in me.

## The stigma will never end...

Yesterday, I was returning from the hairdresser's next to my aunt's house and walking alone, as it is in the middle of the block. A

sound truck was passing by, and I was on the pavement, when the car passed by me, I turned my head and followed it on purpose so that it would be unclear if I were really blind. But, I bumped into one of my aunt's trees with those huge branches tangling all over me, and I was mortified. I got inside, stomping my way in, and told my father to please cut the tree down (laughs). I wanted to laugh at the man who was driving, I lifted my head and walked all confident and full of myself, until I bumped into the tree.

I can see both sides of a situation. I was a person without disability, independent, agitated, with a normal life. Today, I am a person with disability, dependent on others in many situations, with many obstacles in everyday life. I know both sides. There are situations in which I stop and think how the Beatriz from before would think. I also had no contact with blind people, I also didn't know, I was also afraid, so, because I know both sides, I end up thinking and understanding certain behaviours a little more than a person who has never seen before in their life.

A person who is blind and has never seen is guided only by what you tell them as truth. I have memories and many times the reality is not as we are told, it is different. I know how to distinguish between the two sides. I see this as something positive, as an advantage because I can, in certain situations, stop and reflect on how a person's social behaviour was when I used to see and try to remember the expressions they made with their face, eyes, and mouth and try to reproduce them. I imagine that in that context the person could be rolling their eyes at me in that old-fashioned way or shrugging their shoulders and I want to reciprocate in the same way. In the past, I had an easy time with my eyes and I could express what I wanted or not. Today that is no longer possible, no matter how hard

I try, I can put on a frown, the person won't be able to look me in the eye... first because of the glasses, second because I have only one eye left for them to look at. So, I still need to learn certain things because being blind is also learning something different every day.

I am sure that the stigma towards disabled person will never end. A world without stigma is not possible, it comes from a long time ago, it is more likely that the world will end, and the stigma will remain firm and strong (laughs). I don't have that hope. Even if people evolve in the sense of paying more attention to others, paying attention to the other human beings, even if this happens, there will always be those who do not pay attention and who spread stigma. There will always be the one who doesn't care, who passes me on the street and runs me over, who feels better than me because he sees. There will always be something for them to stigmatise. And if the stigma does not end, it is the people with disabilities who have to adapt to the world, it is we who have to change, to take away the cane of a sighted person who blocks our way, to remove the obstacles they put in our way because the world will not adapt to us!

# Conclusion

The construction of Life History, as already said throughout the text, is a democratic and emancipatory process because it is a method that prioritizes listening and respect for the voice of the research participant. Not understood as a mere object of study, the participant plays the role of co-author of his story in which, in a position of equality with the researcher, he constructs, elaborates, analyses, approves or corrects information, decides how and what of his story will be published. Especially with the public of people with disabilities who face stigma and disbelief about their abilities, this method becomes even more inclusive by highlighting the discourse of people who have much to say about their lives and society.

In this sense, Beatriz brought important themes for reflection on her (ex)inclusion in a society which stigmatizes her daily, in a world which, according to her words, was not made for her, but for those whose development occurs within the established standards. Beatriz's speech has an impact, bothers us in the sense of perplexity, moves us, makes us indignant, brings reflection, and finds space and acceptance in the Life History method.

Although, in this book in question, her story had the purpose of exemplifying each instrument necessary for construction, it is impossible to go through it, to listen to this voice without changing and wishing that the world becomes by right also Beatriz's and every person's. Beatriz has a story beyond her blindness and here it has been told, it is up to the reader to decide how to reflect on this narrative,

the role of society and which are its contributions so that other stories find space to manifest themselves, on how to build other stories of lives, of struggles, of confrontation. Using this method with all its seriousness, rigour and scientificality may be a fruitful path for such intentions.

The path taken in the construction of Beatriz's story brought delicate moments and obstacles in which the researchers and participant needed to constantly evaluate, adapt, review agreements and start again, besides reflecting together on the best way to compose the life history with the necessary seriousness and dedication. This demonstrates how complex a method is which, in all its depth, requires complicity, empathy and sensitivity, without leaving aside scientific rigour. We hope that this experience may contribute in some way to those who wish to commit themselves to the exciting journey of building Life Histories.

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Tipologia Adobe Garamond Pro In this book, the reader will become familiar with the step-by-step method for using the Life History method in qualitative research. In a clear and objective way, the authors expose practical examples of each instrument that makes up the method and beyond, the analysis that best corresponds to this type of collection and the final format of the text edited in thesis, dissertation, etc. Taking into consideration the questions that emerge at the time of collecting, analysing and writing the life history and noting the scarcity of literature in the area, this is a guide that brings together all the stages and mishaps that the future researcher may encounter in the process.







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