



PEOPLE IN SITUATIONS OF
DEPENDENCY **LIFE STORIES**



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PEOPLE IN SITUATIONS OF DEPENDENCY. LIFE STORIES

This section of the Report on Social Vulnerability focuses on the personal accounts of people who are going through one of the highest risk and most vulnerable situations: dependency on others.¹

The expressions of these individuals, as a fundamental way of gaining knowledge through experience, are the philosophy that has inspired these pages. Moreover, this expression constitutes the first link in the necessary chain of social participation that will make the problems visible and get them taken into consideration, plan changes and allocate resources, in order to improve the state of vulnerability of many people who are considered “dependent.”

The life story is an approximate description, objectively and subjectively, of the history that was really lived. Our wager with this effort involves “listening” symbolically to the emotional and experiential discourse of people who have no choice but to depend on others every day, listening to how they perceive themselves, how they see everyone else and, in the process, making it possible for them to discover the apparent fragility of their realities. By listening to their stories about their pasts and their capacities, the goal is to determine and propose strategies that will allow them to face their situations and improve their lives and, above all, *to express how they combat the obstacles and barriers that have been placed before them from the outside.*²

In order to orientate effectively the actions associated with social change, it is key to have the experiences and opinions of the true primary actors, assuming that *dependent people are experts in situations of dependency.*

To achieve these aims, sensory, physical, spatial and especially invisible barriers entwined by prejudice must be broken. Unfortunately, the visibility and social participation of people in situations of dependency is infrequent; in part because getting this to take place is a tedious and difficult task that requires time, as well as a bit of empathy and the ability to handle the frustrations. In a society in which setbacks are not usually addressed patiently or willingly, the people who live with special difficulties, whose bodies do not fit into the stereotypes of modernity, efficiency, beauty, youth, wealth and prestige, see their social and living space restricted terribly.³

¹ The expression “life story” entered into use at the end of the last century, replacing “life history”, because the latter term inconveniently did not distinguish between the *history* lived by a person and the *story* that the same person could make to describe this history at the request of an interviewer or researcher. BERTAUX, Daniel, *Los relatos de vida. Perspectiva etnosociológica*. Barcelona, edicions Bellaterra, 2005, p.9.

² “My body was not what was responsible for all of my difficulties; it was the external factors, the barriers built by the society in which I live. I was being dis-abled – they were restricting my capacities and opportunities – because of prejudice, discrimination, inaccessible environments and inadequate assistance. Even more importantly, if all of the problems had been created by society, then society would certainly be able to de-create them. Revolutionary!” CROW, Liz, “Including all of our lives: renewing the social model of disability”, in BARNES, Colin and Mercer, Geoff, *Exploring the Divide*. Leeds: The Disability Press, 1996, pp. 55 – 72, Chapter 4.

³ HUGHES, Bill and Kevin PATERSON, “The Social Model of Disability and the Disappearing Body: towards a sociology of impairment”, in *Disability & Society* Volume 12, Number 3 / June 1, 1997, pp. 325 – 340.

The construction of one's own personal image is a complex process in which individual, family, collective and social aspects come together. For instance, the experience that women have of dependency could be different and more severe than men; this could be due to historic gender inequalities, which have attributed them a series of obligatory "reproductive missions" that cannot be carried out "normally" in situations of dependency. Age and ethnicity can act as stimulating risk factors.

Other invisible limitations have to do with the social discourse on dependency. This discourse is built on everyday experiences, observations, religious interpretations, campaigns conducted by social action organizations and unions, institutional discourses, politicians, business corporations, newscasts and the media in general. Along with these sources comes the belief that it is "*something that happens to others* (and that luckily has not happened to me)," with opinions, assessments and unfounded thoughts (what would I do if...?).

While people find themselves in situations that are apparently similar to those of others, like for instance, living with paralysis or serious disabilities, every individual experiences and deals with these circumstances in accordance to their own experiences, capacities and circumstances.

It is also possible for some people, who are considered dependent by the rest of society, not to recognize themselves as being so; such could be because their subjective conceptualization of dependency is different or because they refuse to admit the severity of their situation out of feelings of pride or shame. In the latter cases, people tend to inhibit themselves from interacting with others *whom they do not recognize as equals*. In fact, studies highlight the existence of a "hierarchy" among people with special difficulties in which those who belong to a group that suffer from some specific complaints, do not want to be classified together with a social group of those who suffer from another type of disabling process (that is, physical, mental, etc.).⁴

Occasionally, due to the severity of their experiences and traumas, some dependent people can lack social skills, psychological stability or basic skills. Attitudes such as having a conflictive nature, apathy, anomy, mistrust, hopelessness usually contribute negatively and in turn generate a cycle of self-exclusion that is strengthened externally by the deepening of their situations.

There are also other factors that contribute negatively like the lack of trust in public and political institutions, the fear that their voices are not heard, exhaustion from not reaching the established goals, the "shame" of having to recognize themselves as vulnerable people in order to demand a particular right or making known a certain need they might have... The paradox of the social participation of people that need to solve vitally important questions (disabilities, dependencies, stigmatized illnesses, etc.) stems from having to first identify themselves as people suffering from or living under such circumstances, which causes a negative reinforcement of one's self-esteem as well as other problems.

In sum, the most difficult and vital circumstances for everyday life, added to the barriers, prejudice, inefficiency and relinquishment of responsibilities in the public sector, along with

⁴ DEAL, Mark, "Disabled people's attitudes toward other impairment groups: a hierarchy of impairments", *Disability & Society*, Routledge, Volume 18, Number 7 / December 2003, pp. 97 - 910 .

an image that is frequently undervalued by, subordinated to or rejected by society, affect their perception of themselves and discourage their social participation.

Despite the obstacles, it is important to point out that human capacities are present even in the worst circumstances of vulnerability because the human beings who face adversity are the ones who can best know their own strengths.

The life stories of the 18 people interviewed represent an exercise in expression, communication and, consequently, social participation. These men and women of various ages and conditions put into practice the saying “the art of winning is learned through defeats.”

Research Characteristics

This qualitative research is based on the *construction of life stories*, and its objective is to study subjectively the phenomenon of disability and dependency.⁵

The World Health Organization (WHO) has developed a useful and practical, internationally recognized instrument, which has helped to diagnose, assess, plan and research the topic of disability, associated with health conditions of human beings.

Moreover, the World Health Assembly (22/05/01) approved a definitive classification: the so-called ICF (International Classification of Functioning, Disability and Health). This classification tries to understand disabilities from a global perspective, as the product of a multi-directional interaction between people and the socio-environmental context.

In spite of the above-mentioned classification, we have observed that there is enormous diversity in the systems of classification of dependencies and, therefore, of heterogeneous assessments and interventions because of the decentralization of the services for assistance to people with dependencies.⁶

According to these principles and this background, a profile for the selection of those to be interviewed was established:

The main objective is to analyze the different aspects that make up the vulnerability and strengths of the subjects, expressing their degrees of dependency and their capacity for recovery, as well as the resources that would help to provide them with an increased quality of life.

To do so, we have used the method of *constructing life stories*. These stories have been transcribed and summarized, and the names and personal information of the individuals were changed in order to respect each selected person's right to privacy.⁷

⁵ The interviews and life stories were carried out by Susana Caballero. Silvina Monteros contributed comments. The transcription of the interviews was done by Elsa Velasco and Susana Caballero.

⁶ It would be necessary to establish criteria for classification, planning and intervention that come from a common language and that facilitate communication among all beneficiaries, professionals and public administrations.

⁷ The objective biography constitutes the comprehensive result of what the person has accomplished over the

Methodology

(Non-participatory) Observation of the places in which people in various situations of dependencies reside (institutions, services, private homes).

Semi-structured interview of the selected people, in accordance with their living environments.

Use of other documents that aided in the construction of life stories.

Compilation of the life stories.

People with the following typologies were interviewed:

- 📄 Aged, dependent people (multiple dependencies: physical, mental).
- 📄 Profiles: two men and two women over 65 years of age.
- 📄 People with severe mental illnesses.
- 📄 Profiles: two men, one under 35 years of age and one over 35 years. Two women, one under 35 years of age and one over 35.
- 📄 People with intellectual disabilities.
- 📄 Profiles: two men, one under 35 years of age and one over 35 years. Two women, one under 35 years of age and one over 35.
- 📄 People with physical disabilities.
- 📄 Genetic:
- 📄 Profiles: a man under 35 years of age and a woman over 35.
- 📄 Acquired:
- 📄 Profiles: two men, one under 35 years of age and one over 35. Two women, one under 35 years of age and one over 35.

Regarding People in Situations of Dependency

Some of the primary factors that were revealed through the life stories, corroborating the characteristics that have come up from the analysis on the vulnerability of people in situations of dependency from Part II of this Report, were the following:

The source of the disability. A fundamental variable that determines the paths of the people is the difference between a congenital or an acquired disability or disease. In the former case, if it is serious, what could happen is that a person's entire life (and that of his/her family) revolves around the disability/disease, with which the person is going to have to live for the rest of his/her life in most cases. On the other hand, if we are dealing with an acquired disability/disease, the main question will be to what extent the person will be able to continue leading the same life as before.

course of his/her life, along with what he/she has not done, what bothers him/her, about his/her family and friends and his/her losses; it also makes a vision for the future possible. All of this forms a part of the person's journey that has been marked by the context and the mechanisms required to adapt to it.

The heterogeneity of the group. The concept of “person in a situation of dependency” includes people with very different problems, ranging from problems of mobility or perception to people with profound mental problems or disorders.

Architectural Barriers. For those people whose mobility is limited because of some motor or sensory deficiency, this issue is key as these are the cause as to why a large part of the spaces in which the grand majority of people travel and live are inaccessible to them.

Social Barriers. Prejudice, discrimination, paternalism and lack of empathy are frequent elements in the daily lives of many of these people, which obstructs their social inclusion and cuts down their self-esteem.

The overwhelming need to rely on others. The lives of people with disabilities and debilitating illnesses become severely limited, and it becomes necessary for them to turn to other people in order to be able to carry out any kind of activity that takes place outside of the spaces that are more comfortable and accessible for them. Family ties and relationships with friends and partners become compromised in this framework.

Becoming invisible. This limitation has an added value, because the scant presence (if not total absence) of people with disabilities in numerous places (places of work, education, leisure, etc.) leads to their becoming invisible; that is, the widespread feeling that there are hardly any people with these characteristics, which makes their problems be ignored and neglected.

A deteriorated image. The isolation, lack of communication and participation, added to the conflict of one’s image of oneself in the face of the prevailing stereotypes of beauty, health and youthfulness, have a bearing on a negative assessment of oneself.

Loneliness. The majority of the people interviewed stated – in different manners – states of loneliness, accompanied frequently by the frustration of not being able to snap out of this circumstance.

As a result of all of these reasons, added to the discrimination that they suffer in almost all areas of their social lives – which range from stigmatization in their everyday interactions to labor discrimination – many people in situations of dependency fall into a process of social exclusion, or find themselves in situations of vulnerability (especially women, who present profiles that are clearly at a disadvantage as compared to men).

AGED PEOPLE WITH DIFFERENT SITUATIONS OF DEPENDENCY

Interviews conducted at the Red Cross in Cuenca – Tele-Assistance Program

The Tele-Assistance Project is set within a broad framework of intervention, which is made up by home-maintenance services and aims to avoid the institutionalization of the users. It is a service of uninterrupted telephone assistance with a specific communications and IT team in which the user has to press a button on a remote control unit or terminal in order to verbally contact (like a speaker phone) the service's control center, which is equipped with specialized personnel who are prepared to give appropriate responses to the user's problem. Depending on the problem, the necessary resources will be mobilized for each case, which range from a house-call visit to the user to the activation of emergency services. The service runs 24-hours a day, 365 days a year. Additionally, the users are permanently monitored both from the Tele-Assistance Call Center – via telephone calls – and through house-call visits by technical personnel and volunteers.

SUPPLEMENTAL ACTIVITIES: Attendance to theater performances (theaters of Cuenca, Tarancón and Las Pedroñeras); Excursions to local towns in Castilla-La Mancha (Mota del Cuervo, Belmonte, Toledo, San Clemente, Alarcón and Villafranca de los Caballeros); Holding of coffee gatherings and discussion groups; Holding of inter-generational activities; Regional gatherings of users of the Tele-Assistance Program in Paracuellos de la Vega, Motilla del Palancar, Buenache de Alarcón and San Clemente; Informative sessions on the "Heat Wave" Prevention Campaign; and the celebration of 100th birthdays.

JOSÉ AND HIS LONELINESS

Presentation⁸

José is 77 years old. He is a widower two times over. He has two sons with whom he has no or minimal contact. He lives alone in a working-class neighborhood of Cuenca. He has a few friends, who are more like acquaintances in his neighborhood. He goes out infrequently, but he likes to take walks. He is retired and receives a minimal pension. He has worked hard since he was very little. He hardly went to school. Currently, he is a beneficiary of the Tele-Assistance and Lunch and Dinner Services of the Red Cross in Cuenca and of the Home Aid Services provided by the Social Services of the area in which he resides.

Familial Context

I was born in X [name of the town], then I came when I was about 7... 8 years old to Cuenca and we haven't returned. Keep in mind...you know? My parents came here to Cuenca but since I was in the field working, I had to plow and we were in different towns [here he is referring to himself and his parents]. When I finished working, I would come to Cuenca, to my parents' house to see them, although my parents died more than 30 years ago.

My father died when he was over 90 years old and he wasn't missing a single tooth and

⁸ Place where the interview was conducted: Red Cross, Cuenca.

he was... well...better than I am. Can you believe it? But then with age, he started to catch any little thing and he passed away. But he was very strong, stronger than I am. My sister died. They operated on her uterus. She got cancer and she's been dead for nine years now.

When I got married I lived in X [he is referring to the other town] but since that woman lasted a month and died during labor....I was....that was so many years ago now, I got married young...She died in labor and the little baby boy, at one month, was really small and the other one was two. One month old...you know? My parents had to take them, I worked out there for them. My father had to take care of them....then, when my father died, we had to place them there in the maternity ward. If my wife had lived, they wouldn't have gone there. I had no other choice, I had to work. I worked every day. I would go and visit them... every Saturday and Sunday but... of course! The feeling is not the same as if you have them with you every day. And then they left the ward, when they were 17 ... 18 years old, and the relationship is different than it would've been if they had been with me every day. You understand?

To tell you the truth...I almost...I placed them there in the ward because I was working. I didn't have them. I went to see them every Saturday and Sunday.

My second wife...well, she was a woman that was alone, you know? And I lived a little up the road and then I would go with the woman and bring her shopping to her and then I said: careful!....I said: 'if you want, we can get together the two of us and we can live happily ever after till death do us part'. Like they say, no? Then she died. We lived together for nine years. She had a heart attack, she died. She died in '97. So, understand [Silence].

In '97, they operated on me and that was when she died and when my sister died too. So....I'm not doing well at all and with my sons... nothing at all, you know?

Social Context

My town belongs to Guete and later we then came here when I was about 7 ... 8 years old. But I was in a lot of towns working when I was young and such. Afterwards, I hardly ever went to my town. Later in X [he names another town], I worked for almost 30 years. There even the cats know me... I'd say! Now I live in a very nice little house in San Antón but I'm lonely. They [he is referring to his sons] live up a bit, and I live down a ways, and they don't come to see me...nothing, nothing! One comes to see me every once in a while but the other one, nothing! [he expresses sadness in his face] not during Christmas or the holidays.

I have friends but I don't go with anybody because I like to go by myself because if they walk a lot, I can't walk... you know? So I prefer to go alone because I stop wherever and I sit down... Do you know what I'm trying to say? There's a woman over there in San Antón, who I go shopping for, she's 84 years old and is a very good person, sometimes we go out to walk. There is also a girl that comes to my house, two times a week, to wash me... today she's coming.

When I had a wife and there was a dance, I was there and always dancing. Ay, ay! When we went to Valencia! Every Saturday or Sunday, I was a dancing fool. She also liked those things. She was a very good woman. Now, I have no wife, no dancing, nothing! I don't go out anywhere, no, no, no... I don't like those things anymore.

With the people from the Red Cross, we might sometimes go to some town out there. Yeah, but I don't like it because they all go in couples or with friends and to go on a trip by yourself ... You understand? Yeah, as if one is a dog tailing behind them... Since you go by yourself... I don't like those things! Before, when I had my wife, I would go but not anymore.

With my wife, I was in Valencia to see that thing with the fish and all that stuff. Now that was really nice.

Health

They operated on me for a heart valve in Madrid, at the Concepción Clinic; it was a valve in '97. They also operated on my gallbladder here in Cuenca. When I had heart surgery, I was all alone, having all of my sons... like I say... It's as if I didn't have them! I was alone in Madrid. I got into the car [he is referring to the taxi], I took the papers from here and they operated on me on September 23rd, it will be ten years now. My wife already had the device [he is referring to the tele-assistance device] and the Red Cross already knew that I was with her... you understand? And they knew my name and my house. And then she died and with the help of a man from here, I got the device. As it turns out, after that, after the operation, they weren't going to take the device away from me. It's a device that you put there [he points to his neck] but you can touch it even in the street. It has a button and you touch it...you know? Then the Red Cross calls me every month from Guadalajara. Every month they call me! To see how the device is working...

Work Experience

When I lived in X, I worked in construction there. I have also worked in the Town Hall, in public works and also in a tile factory. Before that, I was working in the fields, plowing with the mules... you understand? That's what it was before. When I was just seven, I started to work in the fields: threshing, and sweeping to carry grain to the threshing floor. When I worked in X, I earned 500 pesetas a year... of the old ones. I earned that and lunch. But then, the things, of course, well with a peseta you could buy a lot of things. Now, you have 20 euros and you can buy milk, cookies and other things. And they have skyrocketed. You understand? I worked every day, sunrise to sunset, Saturdays and Sundays and holidays. I would have liked to work in a bank, where you are seated and when it's cold there is heat, but we aren't all born to be in a bank.

Training

I don't know much about reading because I hardly ever went to school. Because back then there weren't as many schools and teachers. And as always, when I was 7 years old I was already working, one was threshing...well they had to tie me because if they didn't I would fall, and... come on ... it was because you had to work. Well, yes I would've liked to have studied but back then there weren't as many schools as there are now. A boy, since the time he is little, can go to school and know a lot, much more than an adult. Well in my day, you had to work. Perhaps I can read this printed writing... you know?

He who has an education, man! He always has that degree. It's a convincing thing to do... because he can fit in anywhere he goes.

Inner Life

To tell you the truth, I used to go to mass every Sunday, a lot! When my wife was alive, but – of course – now ever since my wife died I don't go that much anymore because one gets discouraged. You know? Ever since my wife died, I didn't go, I didn't go, I didn't go and I go less and less. You find yourself alone and many times it

makes you very sad and you feel worse. Sometimes I watch television. I don't like those movies with the shootings. I like the bulls, because there almost always are bulls in Castilla-La Mancha. I don't watch soccer very much, but I watch the bull fights! Then sometimes there are those programs, those with the boxes, with the coins, that I like! I also sometimes turn on the radio or put on one of Manolo Escobar's discs, these are the things that I like.

Current Life

Now you find yourself with a worse life, you understand? Yes, because you are alone. During the day no, not now, then you go out to take a walk but, at night! [he makes gestures expressing a feeling of panic] you look up and see nothing, you look the other way and nothing. You find that you are alone, you know? Do you understand what I'm trying to say?

What I'm telling you is that a lot of times, you feel alone and at night you feel worse. You are thinking about bad things. Bad things because you are lonely. Because you are thinking that you are alone, that anything can happen to you and what are you going to do about it? Before, when I had my wife...Many times things happened to her but I could take her to the hospital, but now, not anymore!

What worries me is the loneliness. Loneliness is very bad and especially at night. Bad, bad, bad. And especially in the winter, you can be in there [he is referring to his house] all day without going out.

I may have made some mistakes but not that many, not many...you know? Everyone makes some mistakes but not big ones. You know? Now, nothing, I don't care about anything, dear girl! I tell you, I have food and all that stuff and I don't worry about anything. Man, if I had had a daughter instead of two sons, well then maybe she would've taken care of me.

Vision for the Future

If I'm sick then nothing. I don't realize it now because I'm not as sick, but I realized it when they operated on me in Madrid. Then, I was thinking, my goodness! I'm not going to live anymore, you know? But being as I am now, you don't remember that. Until it happens to you, when it happens then it happens.

Comments on José's Story

José suffers from a huge amount of loneliness and feelings of isolation, he lives alone and does not have the support of his sons or other family members to take care of him, not even to keep him company. This lack of support and nurturing makes José see himself as having an empty life, without any plans for the future. He is satisfied by just watching television, listening to some music or taking walks by himself or sometimes in the company of one of his neighbors.

The qualitative leap that changed his life was the death of his second wife, which was one of the main triggers of his loneliness. The death of his partner intensified his lack of company and his feelings of vulnerability. As of that point, his life has a "before" and an "after": before he could go out, socialize, dance, go to church, etc. Now, he is not motivated to do such things, he is discouraged and feels that he cannot do many things: he is incapable of making himself lunch, going on excursions, etc.

Despite the fact that José receives public aid (the Services of Tele-Assistance, Lunch and Dinner, and house-cleaning), he is generally unsatisfied with his life. Loneliness is his greatest limitation and it is what conditions his state of well-being. The feeling of loneliness turns into a factor of risk and vulnerability because of his lack of emotional support.

José does not show the worst signs of physical dependency in regards to his state of health, although he does show symptoms of depression, which could deteriorate his current conditions in a short period of time. He had a heart attack about nine years ago, but that is controlled through medication and therapy.

José depends on aid to be able to carry out his daily life. He is not capable of carrying out household tasks or of preparing meals for himself in a way that balances his intake of foods that are rich in proteins and carbohydrates. Therefore, both Social Services and the Red Cross of Cuenca determined that José was in need of assistance.

Part of his dependency has to do with his socialization in the traditional masculine role, which has incapacitated him from taking charge of domestic tasks and cooking. In fact, at one point during the interview, he informs us that if he had had a daughter, instead of two sons, then his situation of loneliness would be different. Therefore, José thinks that the responsibility of providing care is still a feminine task.

On the other hand, the lack of other social support, adds to the depressive self-image that José shows, as well as to his low self-esteem. He recognizes that his behavior and self-assurance are less effective than they used to be. He is nostalgic about the past. He assures us that, even though his childhood and young adult experiences were difficult (he was not able to study and he worked hard in rural areas since the time he was a small boy, he was not able to raise his sons...), at least he was never as lonely as he feels now.

CARMEN, HER SADNESS WITHIN

Presentation⁹

Carmen is 65 years old. She is a widow and lives with one of her sons, who is separated from his wife. She has quite an extensive medical history. Her physical deterioration makes Carmen look older than she is in reality. She is depressed over the death of her husband and because one of her sons is in prison. She has few economic resources and her social participation is minimal, as she only has contact with her neighbors. She lives trapped within her family problems and her physical ailments. She is a beneficiary of the Red Cross's Tele-Assistance Service and of some economic aid.

Familial Context

I was born in X [names the town], it's about, at least, 200 kilometers from here. I must've been about 10 when I left the town and now I'm 65; I've been here in Cuenca for many years. We were very close. My mother died when she was very young. She was thirty-something. She died during childbirth with my sister, who also died when she was 39 years old. She passed away right after she was born and my grandmother (rest her soul) and my aunts raised her. My grandmother is dead now, and my aunts

⁹ Place where the interview was conducted: Red Cross, Cuenca.

too, my Aunt Tina, who has also passed away now, had to take her in.
Ay, ay, ay. When my mother died, my brother was 2 or 3 years old and I was about 7 or 8. My brother Lorenzo went to Castellón when he was older and he got married there; he has children and there he has a house. So... I've been suffering throughout my life! Nothing good happens to me, nothing!
In my town, I have my cousins and they still remember me. I have six children and one died when he was 22 years old, he was married, he's been dead for over 20 years now. I have ten grandchildren. My granddaughter, the one whose father was killed... his wife was two months pregnant when he died, my granddaughter is going to turn 20 now in the month of Saints, on the 12th. And then I have the other five and... one of them is on drugs... Oh good heavens!
[she cries].
And he gets out... and he behaves himself very well there and when he leaves there... my dear, he hangs out with the same old crowd and somebody always gets him into trouble. I'm suffering very much! I'm suffering, more than I can tell you. My husband was sick in his chest but the upsets were what killed him first (she says this with tears in her eyes, her voice cracking).
He went to prison when he was 15 years old and now he's 44 or 45 years old. So he's spending his whole life there, all of his youth, my goodness, all of his youth! And we give him good advice; now he hasn't done a thing... not a thing! But he's serving time because of that offense, he came out on an authorized leave from Saturday to Saturday and he went out all morning, he came to the Red Cross to take that stuff... that they take! That methadone stuff. And he came at 11 o'clock in the morning, and he didn't come here at night [she is referring to her house] And there I am suffering... Suffering dear girl! I was so nervous. And I would go out onto the terrace to look for him in my nightgown, to see if he was coming! And then the social worker from the prison called... To see if X [she names her son] had come! And I said... Man! He hasn't come. 'Listen, tell him to report in immediately, right now here!' No, he didn't come for lunch, or to sleep, or anything! I don't know! Later he came home... he came home high... you know what? He was falling asleep. And he was bleeding when he came... he had been as clean as a new pin! He was so clean! Eh! Eh! And I had said to him: What are you thinking? You are going out like that? Now they send for the authorization leaves and they are denied.
That is why the social worker told me: 'he's going to be here a while now, he'll be here resting. He has a year and a half left... he still has to be there'.
But I'm better when he is there. And that is coming from a mother! But I can rest when he's there inside, because when he goes out on the street I'm like this, suffering. He gets together with all of the trash, he hangs out with the worst of Cuenca. It's like, and the one that doesn't do it, is forced to do it by the other one... and that's it! To have a mother say such things! But that's when I'm calm. That's it! I don't have anything else but suffering my dear.
I got married when I was 20 years old and he was 25. And ever since I got married, I've been suffering... my whole life! Because he was sick in the chest, I had him more often in the residence home than I did at our home. How many times did I have to call the Red Cross with that device! And he always pressed the button, at five o'clock in the morning and at six, and he called [she says this with a faltering voice in between wails], so one day I say: Yes I'm annoyed! Well, sometimes, I would travel over a lot of snow to come home from the nursing home to feed my children, so that they would have the meal ready at the right time when they were going to work.
Some days they would admit him, they gave him aerosols, whatever he needed and he

had oxygen at home. They had to install a machine, over in my house, we had to charge it up with the gas canister. So you see, I don't get anything good my dear! He had the oxygen for 13 to 14 years, that's because he smoked a lot before. And he drank some, it was a combination of everything! A combination of everything!... I tell the truth. Well, they released him Wednesday afternoon and on Thursday at 12 noon, my son, the little boy, was crying at home. He went crying to the neighbor, Mrs. Nieves, can you take my father to the nursing home, he's choking, gasping for air! And by then it was a question of time, his face looked like ice, so cold, cold! And the doctor told us: His chest is very sick, his lungs are full of liquid. If he continues like this, there will not be many more Saint Michaels if he keeps drinking and smoking. And he said: 'if he keeps drinking, if he was supposed to last for eight years, he's going to last four or if not, none at all'.

He stopped drinking and smoking [she says this amid sobs]. He didn't drink anymore, not anything. He went to the bar to play cards and he had to leave because he couldn't stand the smoke from the tobacco or the smoke from the kitchen. Because my son has a bar over there in X [she mentions the name of the street] next to the church, and he used to go to see him and to see my grandson, and he had to leave because he couldn't stand it, he couldn't stand it!

My husband, he was good, very good. To be holding on like that, I mean I've been married for 44 years, we were married for 44 years. We've had our ups and our downs, and she who says that married people don't argue, is outright lying! I've gotten angry with him, not fights to kill each other over or anything like that... but many times he put the oxygen on really high.

My other children are very good. The other one wasn't bad dear! –[she is referring to the son who is in prison] but since he tasted it, he tasted that stuff and that was his downfall. He said to me: 'Oh mom, the second they gave me this to try, it was my downfall!'

My other children are married and then there's the one that died. He was killed by glass, he was working as a waiter and he was going to the beach on vacation, with his bosses, his wife and my sister-in-law and my brother-in-law. They were all going, they had an apartment that was already paid for, the days that they were going to be there. And he got killed... for heaven's sake! On the seventh day of the San Fermines festival, it was 20 years ago that it happened. My daughter-in-law was pregnant...yes, just about two months. And he was so excited about it. Regardless of what it was. And he said: 'if it's a boy Mom, Mari [she is referring to her youngest daughter], who was still in my house, will be the one who takes the boy out for walks. And he never met her! And I have a granddaughter who is the spit and image of my boy... Exactly! Just like him, with the same nose. And look what happened to the poor thing, the first time he thought he was going to go on vacation. Look at what a vacation he had! Since then, I'm just not well... I'm not healthy anymore!

My poor son...they gave him many blood transfusions. Just as they would give them to him, they would be thrown away because ... His aorta was cut. He bled to death, he died from bleeding! So you see...what kind of life have I had for goodness sake? I haven't had anything good, nothing at all.

The other five children have come out well, and my husband too, I would get angry with him but he was a hard worker.

Social Context

I don't like to go out, I never go out. Just once when my husband was alive. We went on a trip that cost 1,500 pesetas and my husband said: 'come one, we never go anywhere just the two of us. The trip was for two days. We went to Madrid. That was

more than seven years or so ago now, after I had the thrombosis. And after that, I never went on another trip. I've never gone again!

My neighbors are great, they tell me that I should go with them but I get very dizzy when I go on buses. I get dizzy and it's difficult for me to step up onto the bus! Yes, my neighbors tell me... Come with us on an outing! But it's nothing more than annoyances, you have to go with a cane and the bags. And this arm of mine is useless. Where would I go? Just to bother the people! And I walk very badly. I get tired, my legs hurt me.... And for what? I have to take X [she names her heart medication] at 4:30 pm every day. I have to take a pill in the morning, I have to take the blood pressure pill, I have to take the other one, which I have to take one day yes the other day no. Ah! Ah! Where would I go! And without my husband... since I can't go with him. So you see, good heavens, I've had a lot of sadness.

Health

I had thrombosis. I was coming from having gone to buy milk at the supermarket. I was carrying ten cartons, five in each bag and my son was there [she refers to the son who is separated], he had come home after work. And what happened was that I came from getting the milk and got to my house and this hand [she points to her left hand] got very heavy, stiff and strange. And what did my son do! He went to his room and said to me: 'I'm going to watch the bulls... Mom! I'll watch the black and white one and you watch the one in color in the dining room.' And what did he do....good heavens! He closed the door to the dining room! I was sitting down. I don't know what I was thinking but I got up. I was fatter then than I am now. Before, I was huge, two times as fat as I am now, double! Well, dear, I don't know what made me get up as if I were a feather. I got right up from the chair... I mean I got right up! And given the size that I was, I fell down. I looked like a cat that had fainted. I fell onto the sofa! And I was saying: 'Ay, ay, ay, son, my beautiful son... Help me!' I tried to get up, but this entire side [she points to the left side of her waist and hips] was as if it was like lead, sand, like a sack of sand. I wet myself and all over the floor. And after my son was so worried that he got cold sores on his mouth a few days later. My son, who is already a nervous one, called the Red Cross to get an ambulance. Right then when the ambulance was there, my husband arrived, he saw all the lights on in the house but 'What happened to Mom?' he asked my son. I don't know where my husband came from, everything was open, he went on the motorcycle and the ambulance arrived before my husband did. Ever since the thrombosis, I have to use the cane because I don't have any strength in this arm [she points to her left arm]. I don't have any strength! When I had the thrombosis, I had to go for rehabilitation for some days, but not now. Look at the difference between one arm and the other [she takes off her jacket to show her left arm], and this arm just gets stuck and I can't do anything with it, everything falls right out of my hands. Besides, look at how my legs are [she raises her pant leg a little, enough to see her left ankle]. I don't want you to think that I'm lying! I'm telling the honest truth! Look at the marks that I have, it looks as though... I'm embarrassed by them! Embarrassed to wear skirts! And while my husband was still alive... good heavens! It seemed like everything was indeed attacking me... on the bottom of my foot [she points to the bottom of her right foot] I had a bump like a chick pea that moved from one side to the other. And I went to the doctor, the one from here at the clinic and there they gave me the referral slip to have them operate on me but I didn't realize... good heavens! ... that I had to tell the doctor that I was taking X [she names the heart medication that she takes] and once he found out he didn't dare operate. They say that this... it was a lump of fat, but it happens to be between the tendons and then it didn't hurt me anymore! And now I have

it back again. Because of this before they gave me the orthopedic shoe insoles, they had to drain it about seven or eight times in between my toes. With a needle that was this big [she gestures to indicate a large size] and I grabbed at the doctor, I just about ripped off the buttons on his medical jacket. And my husband was holding me down... and everything! Later, I broke my left leg too. I got up to go to the bathroom and my husband, with the oxygen on, because he slept in one bed and I slept in another that was closer to the window. And that night I got up to go to the bathroom and without realizing it, I knocked over the oxygen tank. And of course, I got up and my poor dear was asphyxiating, his throat was getting all dry. When I realized I said to him, 'my dear, I've knocked over the tank' and he says 'don't worry honey'. At the entranceway to the bathroom there was water or something slippery on the floor and I fell to my knees. I fell onto my knees dear girl! The noise was that of a loud thump, and I got up as best I could...but what did I do?... I went to bed, that was at five o'clock in the morning... And later, oh good heavens, what pain I had in the morning, but even still, I prepared the garbanzo stew ['cocado']...I still put on the cocido! What pain, what thrashing pain! My leg swelled up like a boot. They had to put it in cast. They put seven layers of cast on my leg. It was so much! I was in a cast from the groin to here [she points from the groin to below her left knee]. A month, a month or something like that! Something good... I can't find it because it's been one thing after another. That's for sure!

Later they gave me a curettage, they opened up a file on me, here at the clinic. So it's been a bit of everything!

Work Experience

I've worked little, to tell you the truth. I was working at an inn, a long time ago, where I had to work and clean on my knees and the floors with those rough sponges. I was about 15 or 16 years old, in the height of my life. Then nothing hurt me at all. Now everything hurts me. And I used to wash everything on my knees. Then I got married and I didn't work. And then, of course, I had to do the household chores. Which are quite enough. We were eight all together, six kids and with very little of this [she makes a sign with her hands indicating money].

My husband was a porter, carrying luggage and packages from the station. Then he went to work on a construction site. This was the last job he had because he retired on disability. When he was a small boy, he got sick with polio when he was about 3 or 4 years old, and his spinal column was damaged, it was curved. He had a lump like this, the poor man, on his back bone. They took him to Valencia, to be healed through faith. And there they had to tie him to boards, to belts, they threw him into the sea to see if he could crawl. Doctor Don XXXXXXXX of Valencia, he was the one who saved him. And later they operated on his arm, and his arm was left like this, rigid and immobile, they damaged the tendons and he had a crack in his arm. But with all of this, he worked! That's why my neighbors say to me: 'he worked really hard for the piece of bread he ate.'

Sometimes, I would say to him: 'I'm going to have to get a job washing the stairwells...' And he would say to me: 'as long as I'm alive, it would have to be very bad for neither you nor I to have a piece of bread to eat.'

Training

I've never gone to school. Nothing at all [she says this in a sad way]. Because my mother would go to work in the fields and my father too, and I would stay in the field house, on a farm with my sister [she is referring to the sister who died of chicken pox

when she was very little] my little sister and my brother. And I had to make the meals for my parents, do the grocery shopping and stay and take care of my siblings. So I never went to school, that is what I'm sorry about!

My husband, all of the papers, he took care of all of the paperwork for me! He solved everything. I would've liked to have worked with children, as a caregiver or something like that.

Inner Life

I have a strong faith. Very much so. And nowadays they come to my house, and to tell you the truth, the Jehovah's Witnesses come to my house and I don't open the door to them! Because I believe in my religion and not in them. Because if a son is dying right now and a father has to, and they tell you that you have to donate blood for your son... And they tell you, you can't! That the parents cannot donate their blood. To a son that is yours. One that you've given birth to! Well, no, not for me. I believe in my religion but I don't pray very much.

When I'm sad, I cry and I get very tired [she says this in a low and discouraged voice]. The other day, it felt like my heart was going to jump out of me. There are times when I am very alone. I get all welled up with tears. On Sunday, I was eating lunch by myself because my son [she refers to the son who is separated and lives with her] went to go lend a hand to my other one [she refers to her other son, who has a bar] and I remember: the table that was set, the chairs, and how my husband would sit at the head of the table. And I can't help but well up with tears. And I don't get anything out of it, nothing at all... for goodness sake.

I can give thanks to God because I have some beautiful grandchildren. They have all grown up well! And I have also gone through six pregnancies and not one of my children was born abnormal. That's right, I can give thanks to God!

Current Life

People should be better. I mean, the four days, for the four days that we live, we shouldn't be like this. We shouldn't be envious, or resentful, or anything like that. The same goes for having family and not having it. Life is corrupt and all that stuff, dear girl!

I worry about my health, because as long as I live... but the day that I'm not here anymore, I'm still here for the other one [she refers to the son who is in prison]. Who is going to love him! Who is going to love him? Who is going to love my dear boy! His siblings will not take responsibility for him. They won't take responsibility for him! And my husband, as sick as he was, he was on the second floor, I had him there 20 days, I had him there many times but he recovered. He said to me: 'this time, I'm very sick'. He caught a virus, it was pneumonia that finally ended his life. He was as skinny as a stick. And even while being so sick, while being so sick! He said to me: 'don't abandon that one, don't leave him abandoned, don't yell at him, don't let his siblings throw him out of the house. That house is for him, let him stay in the house, he is the single one, he is the single one. It is his right to be there' [she cries].

I watch a lot of television to distract me. Well, I watch some things that are good, but when they start to show things that are full of murders, and all of those kinds of things then no! It makes me sick. When there are deaths, and when they kill women... I don't like that, and I start to cry! I watch some programs, perhaps 'Dónde estás Corazon', which is on tomorrow on Fridays or 'Salsa Rosa' too. My husband used to say to me: 'isn't there anything else to watch, all these people go to these shows to make money'. My husband died 17 months ago, it will be 18 months on March 26th. My feet and my

hands went with him. My feet and my hands! He kept me good company. A lot! A lot! He would say to me: my goodness! Pray that I last, because you are going to miss me when I'm gone.' And now I realize that.'

Vision for the Future

In being born and dying, God has made us all the same. Just as he who has more and he who has less, we are all going to end up in the big house... as I call it. What do I ask for?. That as long as I can still be of use, while I can't be that good of use, but while I can still be of use...well then! If I take longer? Well good, I keep making my things, without being able to but I still make them. And I tell you, I have some neighbors, who are just wonderful! I don't have a single complaint about them. If I am coming from having gone shopping, they come out to help me up the stairs. And the other day, they carried my cart up to the second floor, I live on the second floor and I have ten to twelve stairs but they help me. I don't want to bother my children, ask them for some things... .yes! But I don't bother them. One of my daughters, lives a little ways past Tarragona, and the other one lives past Madrid. And both my girls say to me, the little one and the other one: Mom, if I was there... closer'. They are both married and have children. I've had many things happen to me dear girl, but now I don't have my husband and my son is in prison. It's a sad life! So...

Comments on Carmen's Story

Carmen is a housewife with a low level of education, with a "traditional" lifestyle for a women in a small town, who is dedicated to the care of her family and has few resources and little autonomy. She lives clinging onto a past that is full of painful situations, which become even more difficult for her to bear every day and lead to an unhealthy aging process. At 65 years old, as she herself expresses, "she has lived through a lot", and she now finds herself in a situation in which she is profoundly discouraged and unmotivated.

Her life story consists of numerous traumatic incidents that are intensified by the gender roles that she is forced to take on at a very early age. She was orphaned by her mother when she was a little girl, she had to help and take care of her siblings because she was the oldest, she had to take charge of her family because she was married to a man that was always in ill health, and she has always had very few economic resources. Moreover, she was confronted by life in the face of the death of one of her sons when he was very young, while always remaining attentive to the care of her other son, who suffers from problems associated with addiction and incarceration.

The emotional tensions of the past continue to be a burden of pressure for her in the present, which makes her see her future as burdened with anguish. She feels powerless and she has low self-esteem.

Carmen looks older than her real age; she appears visibly tired and shattered. As a result of the thrombosis that she suffered seven years ago, she shows signs of difficulty in terms of the mobility of some of her limbs: arm, hand, left leg. Consequently, she must permanently use a cane in order to keep herself stable when she walks. However, the right side of her body does not appear to be affected, neither do her other bodily functions and frames. She

has a good memory, both short and long term, and does not show any problems related to her digestive or metabolic systems.

We can state that it is in the area of her motor skills where she has the most problems, which makes it difficult for her to carry out life's most daily activities. However, she attempts to carry out simple household tasks by taking her time in doing them.

Nevertheless, Carmen only sees her limitations and physical deterioration. During our interview, she told us in detail about each and every medical event related to both her and her husband's health. These manifestations, complaints and physical discomforts could possibly be concealing an underlying emotional state, which could thereby signify she is – unknowingly – adopting a victim's attitude. Such an attitude contributes to a greater dependency on others. As such, Carmen immerses herself in her ailments and other personal complaints.

On the other hand, she does not have contact with anyone outside of her immediate surroundings, despite her friendly and caring nature. She spends a lot of time watching television and only talks with her nearest neighbors. Her degree of dependency is possibly more emotional than it is physical, her self-esteem is low and she has a poor perception of herself.

JOAQUÍN, A MAN IN LOVE

Presentation¹⁰

Joaquín is 85 years old. He lives with his wife in an apartment in the center of Cuenca. He had three children, one of whom has passed away. He has grandchildren and great grandchildren. He has a good relationship with his neighbors and friends at the center. He is retired and he does not show any kind of economic problems. He is very close to his wife and they both attend the Daytime Service provided by the Red Cross.

Familial Context

I'm 85 and a half years old like the mules [he says this with a smile] but I feel just like a kid... in my eyes! But I'm actually closer to 86 years old because my birthday is on January 7th, I was born on January 7, 1921.

I was born in X [he names the street on which he was born in Cuenca], just before the railroad tracks. My mother was from XXX and my father was from XXX but they left and came to Cuenca soon after they were married.

All together we were six in my family, six children and then plus my parents we were a total of eight. What number was I?... there was a sister and then it was me, and then came Manolo, who was a guard of sorts here at the town hall. Then it was José, who was a driver in Valencia. Then it was Valentín, who worked in that stuff, a foreman at construction sites, and then the last one was my sister Mari. I was the second child. The only one that is still alive is Mari, all of my other siblings have died. Well, I don't see much of my sister, she doesn't come up much because she also has a daughter and they have a bar... over there in X [he names the town]. And since she's alone, she goes up there to be with her daughter, who is also alone. Her husband died about three years ago and she's alone... that's why she goes to see her daughter more than she comes to

¹⁰ Place where the interview was conducted: Red Cross, Cuenca.

see me.

I got married when I was 24 years old, yes, when I was 24 I went to live with my wife, who is still alive! Yes! And she is very pretty! Even though I say that to show off. Look at this picture [he takes out his wallet that he carries in his pant pocket]. This is the picture from our wedding day! And this is the one that I wanted to show you because you can see us better in it... this was a day that we were walking down the street and the photographer, it's known that he likes us, and he just took the picture just like that. My wife was wearing a scarf.

My wife is now 83 years old, and I'm 85; I'm two years older than she is. Now we only have two [he is referring to his daughters]. A son of mine was killed by a train, he had a tapestry workshop, over there on X [he names the street]. What a way to find out about these deaths... When the train killed him! [he is referring to a train accident that happened about two years ago in Castilla La Mancha]. That they would make an announcement there, and across all of Spain! And about my children, well we still have Inés and Carmen. One lives in Madrid and the other one lives in Guadalajara.

From my son [he is referring to the one that died] I have three grandchildren, there was one that is a firefighter in X [he names the city] and he comes every week. And then I have another one that was working as a nurse too, she's in a state clinic... and she's all grown up too! And I have the little one, I call him the little one but at 16 years old he's already a head taller than I am! My other daughters are married... Ay, ay! How many we all are now... my grandchildren and we have three great grandchildren.

My children couldn't be any better. We are in a center here, the Cuenca Center II for the Aged, but it's just so that we aren't at home alone. Right now, my older daughter and my younger daughter say: 'Look father! Why don't you come and live with us', and I say to them: 'Why would we go and live with you? and... we don't do anything more than go and take time away from you and the food from your mouths!' And I tell her look: 'since we are in the Cuenca Center II [he means the SED], there we eat and spend the day, and then at night they take us up to our home and they come to bring us back down the next day.... and that's it! When the day comes that we are worse, then yes you will have to take care of us because there will be no choice...

Because I think, I've explained myself well, but as long as we can take care of ourselves, we will stay by ourselves, the two of us, at home.

I have instilled this in my children... what a culture we have, eh? I mean, what good behavior. Very good behavior. Because I'm going to tell you: the younger girl was studying because I earned enough so that they could study. She was studying and as it turned out she still had one exam left in order to become a teacher, one subject left in the old curriculum that used to exist and she says: 'I don't want to continue!' She says... because she has a short fuse, like this [he makes a movement with his body to show that his daughter has a bad temper]. And one day she even hit a boy!... So, as I was saying. And that was what happened to the younger one, she stopped studying. And the older one! She was managing one of those places... that used to be here, a workshop to make sweaters and all of those types of things, she was in charge and since the younger one didn't want to finish her degree... well then the older one said: 'You don't want to study? Well then come to where I work and take care of the office.' And the both of them stayed there until they got married.

First, the older one got married, since he is a printer [he is referring to his son-in-law and he was here at the printers, but he earned very little money and that is why they went to Madrid and that is where they've had their whole family. And the younger one, went and got married to a boy who was a technician of those televisions, and since there wasn't much of a salary for him here either, they went to Guadalajara. And there

they've had their whole family, and later on he started up his own workshop and they have their life there [he tells this happily like he's telling a story].
My daughters come to see us as much as they can. Ay, ay! At Christmas my daughter, the older one, comes and then later, on the day of the Epiphany, my younger daughter comes to us. They come and spend a few days with us.

Social Context

We go to the center every day. We go there and we eat. The van comes to pick us up in the morning, the ambulance, and then later in the afternoon it brings us home. I mean, it's so that we aren't alone at home, so that we don't get bored. Besides, my wife... you see, ever since our son was killed, she just isn't quite right in her head, not quite right in her head [the last words he says in a very low voice, and he points to his head with his index finger] and this is so she is distracted a little more and stuff, and so that we aren't just the two of us alone there.

At the center, I have a lot of friends and the girls that take care of us just adore me. I also have very good neighbors. I have a neighbor who is Basque and she is a hair stylist. You see what happens is that I have always been very handy and when I could see [he refers to his eye sight] and there was something to do or fix in the stairwell, well there you could find Joaquín doing it, or if anything was wrong on the roof... there was Joaquín because I did all sorts of jobs and, of course!... how could they not appreciate me! In our building we are only three neighbors. It has three floors, two which were old and the one that I bought was the most modern of them, it is as old as the years that I've been married, because I got it when they were building it, when I got married and then I bought it and it's where we live. Well, my wife and I get along very, very well with our two neighbors!

Health

My sight is not good, it's what worries me because I go out here, I go out over there and everywhere to all places, and I get along as best I can... And of course! I can't! And there are those that would say, that man! And if I want to lend a hand to someone, I can't do it well. Even though I run around all over Cuenca, starting to walk from here I can get anywhere. Right now, I have to leave here ... I have to go over here, over there [he uses the fingers on his hand as if he were drawing out a route on a map]. And I see the money well, I see the time too and it's now 12:00 pm. Now... but soon no [he says these last words in a low voice, with uncertainty]. This is what I need! At other times I say... I ask the man above: 'Just don't take any more of it away! Don't take any more! Leave me enough to continue to fend for myself!'

Work Experience

My trade has been that of an auto body worker. I've worked as an auto body worker my whole life! When I went into the army, I was lucky to have been in the military for three and a half years... don't you think? And there I worked in the auto body shop where they made all of the automobiles for all of the ministries, and all of the ones for the army. And there I was like a militarized compatriot. Later I was given a degree and then there was a workshop for bodywork, I would have stayed there as a militarized compatriot but later on my family missed me and then there was a little shop back home and... I got myself a job there! And I started to work... and then in a shop like that one I was telling you about I was working for 25 years and then... we did full bodywork for buses but then some guys from Talavera took it over and then they went ... and up and left! And then I got a job at Renault. I got a job at Renault cars too! And I worked

there for another ... 25 years. I'd say that I worked, in the military I worked for three and a half years, and then later there well, I was some twenty some odd years in one place and twenty some odd years in the other place.

And imagine how well I did that when I retired, they gave me a watch. They paid a tribute to my wife and to me... in a big way! They gave her a pitcher, a tray and things like that and... and bouquet of flowers that was bigger than she is! I mean, they really treated us very well, very well!

Later they wanted me to keep working, but I said no! As I said, I retired to be able to spend time with my wife, I have a salary that is enough for me to eat, so the job can be for someone else. That's what I did, just as I'm telling you.

Then...I, of course... during the time that I had free when I was retired, I had my car and I would pick up and go to see my girl in Madrid [he is referring to one of his daughters]. Or to see the other one in Guadalajara! [he means the other daughter]. To see my brother in Valencia! I drove very well, I've never had a single accident.

Training

I graduated from grade school and then I got my university degree in the army and I learned my trade as an auto body worker.

I earned enough so that my children could study but the youngest one discontinued her studies to be a teacher. What's for sure is that when my children went... education wasn't like it is now. My grandchildren, they've all, or almost all of them have a degree. The ones that don't have any education, have learned a trade.

I haven't studied a lot but I have the knowledge and common sense that life gives you. I've dealt with a lot of different kinds of people, throughout all of those years that I worked, first and foremost, I had to welcome the clients, and get the job done... and they would double my salary! I'm used to dealing with people, and not getting to someone and saying: Do this! Do that! Or whatever! You've got to have a little of common sense.

Inner Life

I'm not one of those who is at church every day... but I've never let a Sunday go by without going to mass with my wife. Every Sunday I go with my wife to mass!

Because... life has given me everything! I don't begrudge anything! Nor do I hate anyone! The only problem that I have now, I bet you don't know?... You can't imagine what I have? I'm there in the home and there is a man there who is despicable [he says this in a low voice and in a disgusted way]. He speaks badly about everyone uses words that I've never even heard before. And the man gets into an argument with one, and then looks for an argument with another one. And I already told him the other day: 'hey, listen...don't talk to me!...' And I said it to him in a formal tone and I said: 'act as if I weren't even here.' And I said so to the director and I also told the girls that take care of us. I forbid this man from talking to me. I talk to the girls... they adore me because I'm lovable and stuff like that. And besides, I have a bit of common sense, but this man...and I won't even tell you more about the ugly things he says about the girls! And why would this man say such things. Right? They are cleaning his behind! [he says this in a low voice and warily]. He has a very bad attitude.

Current Life

At the center we do a lot of things. So much that.....well, there, you talk to one, then another, later they have you to do odd jobs that are very good. They have me to do some calculations even though my sight is bad....XXXX operated on me....I don't

know if you've ever heard of him before... well if not I would've gone to Madrid... after him I was completely blind.

I do calculations very well, and then they give you designs that you have to fill in with paint, and they also give things to my wife for her to do; I mean we are very well entertained [he says this energetically and optimistically]. Besides, every day we have exercise class, we have a half hour of exercise even though I – I don't meant to show off – well, I, as soon as I get up in the morning at home, I do 23 different exercises, and I'm not just saying that to say it! Look! [he gets up from his chair where he was sitting, he pushes it a little out of the way and he starts to do exercises, he appears quite flexible and strong]. Do you see how I can bend over, and move my arms and my legs? Twenty-three moves! Every day! And then everything that we do there [at the center] and the day that I don't do it I feel as though something's missing!

What worries me, is my wife! Because since her head is the way it is now... They were treating her and now they have stopped because they saw that she wasn't getting any better... She is the same!... Now she does actually sew things, and she cooks a little... a little. And I say to her: 'Encarnación... even though I have problems with my sight, and I can tell the time because now it's 12:00 p.m. ... well I am luckier now than you...' because, this is what we've got! [silence].

I've thought about it and I'm fulfilled. Because it was all about making the best life for my children so that they could get ahead... and living without having to have my wife go out and work! I've earned what I had to in order to take care of them, not only just to eat, but to enjoy ourselves and other things too... If I had to work two more hours, I worked two more hours in order to get my family by.

In spite of my sight, of course I watch television. I can't distinguish very well what I see but I still spend some time watching it when there is a soccer game on. I like those a lot! I also like to watch the bulls, but now I like to watch soccer more because I used to play soccer a lot... for many years, eh! Then, when I got married, my wife says to me... eh! No more soccer, because at that time you didn't make the money that they do now in soccer. Now, being a soccer player... well you earn money, but back then you played for nothing! That was my hobby, that and fishing... oh... my fishing rod! On Sundays instead of going to the taverns like most other people, to the card games and things like that, I would get out my fishing rod and hop in my car and I would go to the banks of the river and go fishing for a while. And my lady or my wife... lady is better said but 'my wife' is more common these days... She would say to me: 'look, go wherever you want to go, the morning is yours, but the afternoon is for the two of us.'

Vision for the Future

Well, my death will come calmly. Well, I think that I am going to handle it well. I tell my wife: 'the day that I lose you, I will already be dead!' I have a wife... eh? To whom I have yet to ever say: 'Get out of here!' And that is an expression, you know, that is very common. 'Go on and get out of here Encarnación!' I've never said that to her [he is moved and his eyes well up with tears]. I don't know. That's what I'm saying, and it's the truth, I don't keep track of things and if I'm lying, then may God take away the little life that I have left to live!

Everything has been fulfilled in my life. If ever, if I ever look back, on some things, even though with the apartment that I have... I live in a good place. The only thing is that... that at some point I've said to my wife: 'hey listen, why don't we buy another apartment... eh? In case we ever need it, or just to have it there... But that's the only thing. She never allowed me to do anything like that, because I've only ever had a few bucks to my name and I would've liked to have moved them around a bit like that. And

my wife would say to me: 'we have done our children well!'
And like I was saying, I got married and I worked a lot and in terms of my children, each one of them had his or her own money. I made sure that what they earned was for them, for tomorrow. I would say to them: 'what you earn goes into the bank... also, what you earn is for you for tomorrow'.

Comments on Joaquín's Story

At 85 years old, Joaquín finds himself going through a healthy aging process. In reconstructing his life story, through his own words we see how he had a healthy childhood, not only because his basic needs were met, but also because he had a family that provided him emotional well-being and stability. Throughout his life, we see how time and the accumulation of his years come together and move in the same direction; that is, one of stability and normalcy. Following other periods of his life, we see how he left his nuclear family to do his military service; later, he then married and worked, having done the latter effectively and receiving recognition for his good work. As he himself states: 'I got my kids and my family ahead.' Now that he is retired, he enjoys this period by doing what he most likes to do; he goes fishing, he takes walks with his wife and trips in his car.

The fact that the course of his life took place without any major twists or turns or significant changes in his professional career or family life, favored and strengthened his acquisition of good habits. Joaquín has learned how to encourage and implement physical and intellectual strategies, out of learning resources, which have allowed him to keep himself in good shape and to be able to communicate and interact well with his family, at work and in social settings.

His loss of sight is one of the issues that most concerns Joaquín. While he may accept it with a certain degree of resignation, we find that this situation limits him and from time to time he gets frustrated when others decide to help him. This is what the program manager who knows and works with him told us.

Currently, upon finding himself with reduced vision (which is actually more deteriorated than he himself admits), his area of movement has also been affected, as he now must depend on another person to walk and get about in unfamiliar places, or to go up and down the stairs. He can carry out very well voluntary motor activities and he likes to do exercise; however, he does have a small amount of dependency in terms of going from one place to another and in being more efficient in new places. Nevertheless, he does not need a cane or walker in order to get around.

Another issue that worries Joaquín is his wife's state of health. He is in love with her, he has stated that they are both very close to one another, emotionally speaking. He does not refer to his life, without doing so through his wife. Upon talking about her, he gets emotional and he values her very much as a wife and as a mother. His wife's loss of memory also affects him psychologically, as he has not managed to internalize this loss and this is an area that should always be reinforced by his caregivers at SED.

Joaquín is a person who is very full of life, who likes to find ways to entertain himself and do new things so that he doesn't get bored. He is aware of his age and of the changes in his body, and he also has a serene attitude towards his own death.

The social support that Joaquín receives in the Daytime Assistance Service is extremely important for him, because through it he feels that he has greater autonomy for himself and for his wife. The social support is meaningful, not only as a source of psychological and social well-being, but also because it has important effects on the promotion of good health and the prevention of illnesses.

The center creates a setting for communication, thereby fomenting relationships with others and encouraging Joaquín to be both assertive and empathetic in his verbal and non-verbal communication. At the same time, the center strengthens the social ties that he already had and encourages all kinds of pleasant activities. Taking into account Joaquín's advantages and limitations, his degree of dependency is of a lower level, which is partly due to his personal history, and partly from his emotional stability – which allows him to be able to continue living with his wife – and lastly, it is also thanks to the external support that he receives on a daily basis.

ELVIRA, THE LIFE OF A CAREGIVER

Presentation¹¹

Elvira is 79 years old. She lives alone in a working-class neighborhood of Cuenca. She has a strong faith in God and is a practicing Catholic. She suffers from osteoporosis in her spine and, because of this, she has problems in her neck. She is a user of the Red Cross's Tele-Assistance Service.

Familial Context

Ay..ay! I'm going to sum it up for you, I'm going to tell you very quickly because even though I was less than ten years old I remember exactly what happened to me. Well then, I'm going to begin. I was born... my parents are from a town called X [she is referring to a town in the province of Toledo], well, my father wasn't exactly from there, he was from X [she cites another town in Toledo], but it doesn't matter if you mark down that he was from X [she is referring to the first town she mentioned] because he married my mother who was from there, ok? Well then... but I was born in the town of X [she mentions a town in Ciudad Real], but when I was a little girl we went back to my mother's town. I spent my childhood there: with my mother, my father, my aunts and uncles and my grandparents. But since my father worked in the postal service, they stationed him in that town in Ciudad Real where I was born even though we later returned again to X [the town in Toledo].

We are six siblings, I was the second. First there was my sister Julia, then I came and when I was born my father looked at the calendar and he said: 'look, today is Saint Elvira's Day!' My Saint! She is buried in the catacombs in Rome. I was born on May 1st.

Well, when I came to Cuenca... I must've been about twenty something years old, I don't remember exactly how old I was... well, I could've been 24, 25 or 26 or something around there. I came to Cuenca because I had health problems and they had to operate on me, and the surgery that I had was here [she points to her right leg], which was ... well now, it must've been about 1955. I had surgery on my spine and I came

¹¹ Place where the interview was conducted: Red Cross, Cuenca.

because I wasn't well and they had to operate on me and out there in the town they didn't have the means to do it and, through a nun that would often go to X to visit a lot... and look, she said: 'I'm going to fill out some papers so that they will operate on you in Cuenca – because my back hurt me a lot – to a good place where they perform surgeries on bones.' And they operated on me here. My mother died... it must be about 17 or 18 years ago now. She died when she was 85 years old. Yes! At 85 years old! Well... with my siblings, you know what happens, I'm old now... And I don't like to travel; my siblings are in Madrid; I have another sister who is younger than I am and she is in a town in Toledo, she is really old, she's in a home for the aged, it's good! But... you know? We talk but we aren't together... of course! We talk every once in a while, and every now and again she comes to visit me.... I have another sister too. Here in Cuenca, it's the two of us! The eldest is single, she's working in a house, she's been working there for 50 years! Fifty years! In a house. She's with the old parents. She's with the old parents! They are now old but they treat her as if she were another one of their children. They only have one daughter... and she is married now. And so you know what I mean... my sister says she can't leave them because she would be too sad to leave them alone now that they are so old. So, for the time being, she is there. I'm single. Well... I think that if I had gotten married that I would've been a good mother and a good wife... I'm not boasting. Well... I know how I am.... so.... everyone has to know themselves and I know what I'm like! Eh? I would've been a very responsible person... if I had had children, with my children, but then again, it's not like anyone made me any proposals... Since I lived with my mother, and I know what she did for us, I said: 'My mother comes first', and that's it! Enough said! Well then.... but I would've been a good mother, very responsible... A good mother!

Social Context

Well then, I have very good neighbors and I get along well with them. If I need something... I know that they will be there. I have a neighbor, who has a copy of my key, the key to my house in case something happens and in case I leave the house without my keys so then she can give me the other set. This has never happened to me but... they're there.

I'm a very good friend to my friends and besides, they can count on me to lend them a hand. At the parish, I have a lot of friends, we see each other almost every day. I go out with Carmen every day to go for walks and this is good for me.

My most dear person, the one I hold most dear! Because it's with whom I've been my entire life, is my mother. She's the one.... my mother! She is the best, and besides, she was a wonderful mother. A mother to all six of us and she always took care of us in any way possible because she was always watching out for us. Even if she didn't have the means! What was important was that she was always there! There she was! For me the one I'm most grateful for and the most beloved person, is my mother. She's had a great influence on me, because I've suffered with her, I've worked with her, I've done everything with her! So, the person who has had the most influence on me and the person that I have loved the most and who I continue to love is my mother [she is visibly moved].

Health

I suffer from quite a lot of pain in my bones, my lower back and my neck all hurt me quite a bit... but oh well, since I move around a lot because I have to move around, of course! I must move around because if I stop, well then... well, I move around quite a bit. Every day, whenever it's possible, almost every day I go walking for about an hour.

Yes! I go walking for an hour and I am always active. Besides, I've been operated on three times for a hernia, a hernia in the groin muscle, that is something that when you have it you don't have any strength. I've also been operated on my spine... many years ago, they removed my tibia and they did some bone grafting there in the back [she points to her spine]... I mean... I've had surgery on this breast [she points to her right breast and she laughs]. I do well for my age, I do well because I'm always moving about.

Look, do you see these fingers? [she shows her fingers on both of her hands], they've become deformed from the arthritis, but since I do exercises, I do things with my hands... This is very good to do! And moving around when I go walking, well, I also do exercise ... so it's...

What I can't do is lift weight. A woman who also lives in my neighborhood goes to my house to help me and she does all of the heavy lifting because... it's not good for me to do it anymore! No going up or down the stairs. Now, in terms of taking care of the house, to take care of myself and to prepare the meals, this I can do myself. That I can do! And I continue to be able to do it and thank God, that's for sure, my head is doing quite well...

Besides having the woman go to do the cleaning, I have the little telephone, up until now... they have been calling me once a month, they call me on the first day of each month... They also had been calling me during those days when we had the heat wave. They call to see how I'm doing... then they told me that they were going to call two times, on the first of every month and in the middle, like on the 15th for example. They also call us to wish us a happy birthday, always on that day, mine is on the first, but if someone else has a birthday on another day, they call them to wish them a happy birthday too.... I mean, I'm very happy. They are very lovable those girls, and they are very attentive to us old people. That's ... that's very important to us!

Work Experience

When I came to Cuenca for the operation on my spine with my mother... I've been living here for forty some odd years. I was with my mother the entire time. I was working in the same hospital where they operated on me, the two of us, my mother and I. The Santiago Hospital, which still has sick people and that back then was the only center that there was in Cuenca. All of the sick people used to go there back then, and there they operated on me. And then when I was better, I worked there with my mother in the kitchen.

Yes! Because.... And then they gave us those apartments, and we've lived there ever since. My mother, at first when they offered and gave us those apartments, she was quite well, she... I mean, she did the grocery shopping, she did the household chores, she went to mass every day because she had a strong faith and was very devout, she went to mass every day. Later on, as time went by, she started to forget things around the house.... Anyway! And then until she died, I helped her... I've spent my whole life with her!

I worked in the kitchen at the hospital for many years. I have a pension... why yes, I do have a pension... it was the pension that was given to my mother, and since I'm single and I was with her, it's the same pension that they now give to me. My mother was working there twenty some odd years, she was working there the whole time and then when she died, they gave me her pension.

Training

When we were in the town in Toledo, it was the time of the civil war, and my mother

became a widow because my father died in the civil war, at the end of the civil war. I must've been about 9 or 10 years old, yes, that's right, 9 or 10 years old. And we had quite a hard time! Eh, eh! [she says this with an ironic smile]. You know? We had some very hard times. And that's when our schooling was interrupted. If there was a school around, then those that had a little money would go, because those of us who didn't have money, we had to go and work in the fields. When we couldn't make ends meet anymore, my mother would send us off to work or if not then I had to take care of my younger siblings.

What I know, if I've learned anything.... I'd say, it was in a course when I was already quite old... in a school that is right next to my house. It was a course for adults, and I learned how to keep track of the bills, I learned to write a little, to read, I read a lot because I really like to read. And I haven't had any schooling! What I know is how to get by... that's it! Because I never had the chance to study... That's just the way it was! I really like history! Ay, ay! I just love history... but oh well, since I never had that opportunity, I don't know what I would've chosen because I love it.... Let's see if I can say it... the army! [she laughs] Who would've thought it? Perhaps I would've gone into the army. I love the army! I love the discipline that they have there, because on Armed Forces Day, I watch television all morning long. Don't think that everyone knows how to give orders. Giving orders and doing it well! Eh? Giving orders and doing so with justice... that's where it all comes together. And it doesn't mean saying... 'here, you do what I tell you' ... no! That's not how it's done; one must know how to give orders, and do it well. Well then, I like discipline, and when those line formations march along in the parades, I get very excited! I like how everything is perfect, there, everyone doesn't just do what they want to do.... It's not like how things are done today. Like how children today don't listen to their parents, or do anything. So, I am a person that likes order, I like it when people take responsibility for their own things. Why is today's youth so lost? Why are there so many drugs? Why are there so many murders? Why do such terrible things happen? It is because today's youth... are not as informed as they should be! Eh! Thinking a little about one's neighbor, about others... Today they have it all served to them on a platter! If the children are not cut out for studying then why do their parents force them to do it and spend their money? They should make them work! ... Don't you think?

I get very annoyed about the drugs out there, all of those deaths that there are with the women. The abuse that exists against women, the husbands who think that they have the right to do it... There are so many things. I don't like war! The war in Iraq... how they are killing children, massacring now so many people... because the United States or whoever it was, just decided to create a war that doesn't make any sense whatsoever! Eh! It really bothers me!

Besides, I am a nature lover and the fact that they are poisoning everything... they are poisoning the seas, the planet! It drives me crazy. I am quite a nature lover and an animal lover! Why do some people hate animals? I live in a neighborhood and there are a lot of people who hate the birds, they scare them, and if they could they would kill them, it bothers them that they are perched on the trees. I don't know! There are many things that bother me.

Almost all of the books that I have at home are about history and I've read every one of them. Sometimes I read the daily from Cuenca, when I have a chance, I usually read it. I don't buy it because it costs money and the pension I receive is small and I don't buy it every day. But, if something comes with it that's extraordinary, like, for example, something about the festivals, if it's something that interests me then I buy it. I usually buy it but... I mean... in general I don't buy the newspaper! Well... I also have about

two or three books about the Pope.

Inner Life

For me, God is everything! I know that he is what gives me the strength and the morale that I need. And besides ... I'm convinced! He is here with me at all times! I say, when I'm walking, I say: 'Lord! You are with me! Because I can move, because I can see and because I can hear'. I have a deep faith, and I truly believe, very truly, I believe in the Lord and the Virgin. I know that they help me! I am alone but I am not alone. They are there! They are my strength and my morale!

If I get sad, I know that they are there, but it's just that... I am a person who has my ups and downs, of course! I get sad sometimes, but I am the type of person who looks forward. I have a lot of determination, I like to do things, when something happens that seems overwhelming, I say: 'I have to get over this.' I am a person who has a lot of energy. So, in regards to God, I am totally convinced and sure that he takes care of me. I say: 'You are taking care of me Lord! And you give me the strength and the morale that I need.' And for me, that means everything! It's that simple!

What makes me suffer the most is the war, emigration, those people that had to leave their respective countries to go out there wandering about. All of those people who are dying in the seas, who break their backs trying to get somewhere else. I don't know! But this is what makes me really suffer, I am a very sensitive person. And then, since I've also had a lot of needs and I've experienced hunger, I know the reason why these people throw themselves out there, without thinking about what could happen to them along the way. And in this respect, I suffer a lot. I suffer a lot! I worry a lot, I say... I ask the Lord: 'why does all of this have to happen? What's going on?'

I think that what's happening is that we people, are not good. There is a lot of selfishness, some have everything and others don't have anything at all. It's that simple. So, then... I suffer a lot for all of these people.

Current Life

I am always on the go. I am in the parish too, over there... the one next door to my house. The parish where I volunteer is La Paz. I volunteer in everything that I can ... not with bills and things like that, of course! Well, over there in the parish there has always been missionary sisters from the XXXXX, who always ran the whole show. So, of course, the preparations for mass must be done, the chimes must be cleaned, everything that has to do with a parish. Also, you have to keep an eye on the purifiers and the overall upkeep of the church. The altar, it must be cleaned often, it must be washed down and dusted and things like that. Many things must be done, everything that gets dirty there, must be taken and washed at home. There are also baptisms and weddings and everything must be done in preparation for them.

We have two groups. Some go in the mornings to clean the church and another group goes with me in the afternoons. Well... in the mornings, the women wash the floor because I can't even lift up the buckets, I can't lift any weight, but in the afternoons my group and I do everything else.

Well... the difference between life today and back then is that we don't appreciate what we have today. I've had to earn the bread that I put in my mouth through my own work and sweat. I am grateful for what I have, I appreciate what I have! In my day, parents were respected, and so were grandparents, not anymore. People have become very careless. The streets, we think that the streets are our garbage cans, people walk their dogs in the parks... the parks are very well taken care of because the town government takes care of them, a lot of money is spent doing so, then they go and run over

everything ... they break down the lamp posts, they destroy the benches, the garbage cans ... That makes me very angry!

Today's youth doesn't appreciate what they have. They don't see it. Because everything has been handed to them. Hey, here! Take it, take it! Children must be raised well and be taught good manners. Even though I'm not married, I've been through a lot of things and I had to take care of my younger siblings, so they must be brought up with honesty, and telling them: 'you have to take responsibility for this and that'. A good upbringing... and then they will go through the streets respecting the things around them.

And the television ... What terrible language! This is also something that really bothers me, the television isn't an example, and I don't mean that all of the channels are bad, but there are several. There are several!

I always watch the newscasts; I like to be informed. I try very hard not to miss the newscast. Also, if I can, I try to see all of the programs that are cultural. I watch channel 2 a lot because I am a nature lover, I have all of the tapes of Rodríguez de la Fuente. It's such a shame that that man died! He was doing such a good job ... but, oh well ... his work is still there! What he did is still available! And now there's another man on channel 2 ... and you know what? He has a similar voice! You know? I like documentaries, things that have to do with nature, cultural programs, I always watch them when I have the time. Now then, I can't stand the gossip programs, those channels ... where they go to sit down and talk about things that no one even cares about. They are journalists that have no morals ... That really annoys me! [she laughs] And they curse, because on public media outlets you should be well-mannered. You can't just say those words, because there are children, and those scenes with all that kissing and cuddling... At any hour of the day! But ... I mean there are children watching! Those who direct the channels have to be more responsible. If the children don't learn good things, then we'll have lost everything ... And the parents... there are a lot that aren't like that, some of them are very responsible ... others let their children watch everything. They let the children do what they want ... That's not how it works... eh?

Vision for the Future

When the Lord calls me, I will go; I am not afraid of death. I just ask that I don't suffer a lot and that he gives me all the strength and tranquility that I need in order to accept it and to let it come easily.

Well ... it's not exactly a dream, but since I was born in X [she is referring to the town in Ciudad Real that she left when she was a little girl] well then I would kind of like to see it, I don't want to die without having known X, which is where I was born. And ... right now this is something that I've been thinking about over and over again, and at some point ... well ... I'm going to call upon one of my nephews, because I have a nephew who is just a doll. I'm going to say to him: 'go get the car and take me to X' [she says the last part jokingly]. 'I don't want to die without having seen the church where I was baptized and where my papers are.'

Comments on Elvira's Story

Elvira looks younger than her age of 79 years. She has hardly any wrinkles, she is slim and elegant when she walks, even though she carries a cane that is meant to aid her in having greater stability and balance when she walks.

Throughout her life's story, we see a historical context that was marked by the civil war and the effects of these events upon her family unit. She lost her father when she was a little girl, and since she was one of the oldest sisters, she had to help take care of her other siblings. Taking care of them, doing housework, working in the fields and stopping her education were all events and traumatic situations that were typical of the times of that period, which determined the destiny of many families, especially those of women.

Elvira would have liked to have studied, to have been a historian or an army officer, she would have liked to have known more, to have been able to get by more effectively and with greater efficiency. Even still, as an adult, she acquired a school diploma by going to adult classes, which was confirmed to us by the program's managers.

Currently, Elvira has a dynamic life, she not only is concerned about her health, since she tries to take care of herself, but she also participates actively in community life. She works diligently and with dedication in her neighborhood parish, she takes an interest in and is upset by things that do not work well in society; about how badly parents raise their children and about the lack of "civilized conduct" that society has in general.

She seems very active and participates a lot because of her profound religious beliefs, which allow her to understand and justify life according to those principles. Her sense of spirituality in the Catholic faith is a valid indicator of her inner life, which signifies a healthy evolution in the future. She is a conservative woman, who was raised under the codes of her time; however, a healthy aging process is easily observed in her.

While she does show a gradual deterioration of her bones, and her vision has diminished, her degree of dependency is slight. Her healthiest aspect is her inner strength, her will and her energy. She has the logical health problems of someone her age, but she is not vulnerable; to the contrary, she displays vitality and empathy with her life.

Her social life is very active, since she says that she only watches television when she has time, she works at the church every day and, within this context, she receives the emotional and relational support that she needs. Moreover, she has the resources to maintain and strengthen her friendships and her social fabric.

Only her advanced age, and the fact that she lives alone, become factors of vulnerability, more than anything else in her life in the future. Through Social Services and the Red Cross, the Tele-Assistance Service has been coordinated. This preventive measure, encourages and provides support for the health care and social support that Elvira might need in the future.

PEOPLE WITH INTELLECTUAL OR MENTAL DISORDERS

Interviews carried out at the Gil Gayarre Foundation

The Gil Gayarre Foundation is a private and public residential complex that receives funding from the public administration as well as from a religious congregation. Its intense activity with people suffering from intellectual disabilities is recognized beyond the borders of the Community of Madrid. The following services are provided:

Service: Special Education: with 15-18 students.

Service of Occupational Orientation: with more than 200 disabled people in the workshops.

Service of Residence Facilities: 3 residence halls that are distributed by units, as per degrees of autonomy.

Service of Assisted - Living in Majadahonda: 2 apartments, one for boys and another one that is coed.

The overall operation was observed of each of the residential units, which were all visited; moreover, they served as the location for the conversations with the caregivers and the interviews with the selected people.

VÍCTOR, HIS HOME AT THE RESIDENCE FACILITY

Presentation

Victor is 47 years old and ever since he was 14 years old he has lived at one of the Foundation's residence facilities. He is one of the residents who has been at the institution the longest; he is known as and is considered the "boss" of everyone. His diagnosis is a slight intellectual disability as a result of the possible effects of polio.¹² Also, during puberty, he was diagnosed with a degenerative disease that has affected his mobility. Currently, in order to get around from one place to another, he uses a motorized wheelchair.

Familial Context

I've been here since the year 1974, I lost my mother during childbirth. Right when I was born... she died ... and my father died in 1983.

I have two sisters, they don't come to see me, nothing [he makes a sound with his mouth as if to say no].

No one comes and I'm just fine with that.

Social Context

In my unit, there are four of us. I live over there in that residence hall. But what

¹² Polio is an infectious disease that is caused by a virus that has a special affinity for the upper canal of the spinal cord and causes motor paralysis, without affecting the sensory feelings or vegetative functions. Source: Glossary, www.discapnet.es.

happens is that we can come and go ... so we aren't out of touch ... [he is referring to the adjacent unit, which is the boys' quarters that is next to the main facility].

At the facility there's Igor, Alfredo, Ignacio, Fernando, José Luis and I. I don't remember the others. There are about seven or eight of us. Well ... you know how in every house there's always a few problems. Well, look ... the truth is that we get along well. There are days when we are a bit worked up about something because ... not because we want to, because ... it's a lot of hours and we want to rest but we just can't. And as a matter of fact, we rest, but if they come to ... it's seven or eight hours of working over there at the house and you get tired. And then say... if you came back to rest. And then someone comes and goes to your room, it annoys you and then if they want this, then they want that. I mean: 'I want to rest!' Eh? If you aren't tired, do whatever you want; but let me rest'.

Also, when I was at the camp on vacation, I made some friends who said that they were going to come to see us, but since they are studying and stuff, well ...

I am very happy with the aids, they are very nice to me. Well, no problems... A small problem might come up now and again, but ... it gets resolved by talking, that's what I say.

Here, you get along with everybody, you may have some ups and downs now and again but you get along well. You are happy. I get along well with everybody, but what I can't do ... is put on a good face for everyone. If things don't work out for me one day, you don't have to ... the only thing you need to do is help ... and stuff, no? Come on, I think ...

Health

I wasn't in a wheelchair when I came here when I was 14 years old. I didn't even know what a wheelchair was then. And when I realized that I was sick ... I said: 'I'm going to go to the doctor for him to see me. Let him take a look at me and tell me what's wrong with me.' Well ... I went to the social security and in the social security office they diagnosed me with a cyst that was 14 centimeters big, but they told me it was from playing sports... I mean... Look, you don't get a cyst from playing sports. Because I played a lot of sports. Well ... yes, because you have a cyst that is 14 centimeters and it's from playing sports. I said, no. I'm not going to risk it. I came here; we would turn over the report to a professor that I had ... I did a lot of physical education with him and he says: 'this isn't normal.' You must have something in your back because this isn't normal. Well... so I went to the Concha ... to that hospital [Hospital de la Concepción]. And there they made me take off all of my clothes. As soon as I got there they started taking off my clothes and I said: 'but I came in for a check-up!' 'No! No! You have to take off your clothes, and this and that. They took some blood samples, my blood was fine, my urine was fine, my lungs were clear, my heart fine... And I had the cyst. And then they did an MRI, which I don't like because... you are there, and you are enclosed and you can't move. You are stuck in there for an hour and I said: 'I'm drowning in here, I'm suffocating ...' Yes, yes, yes ... And I had a cyst of 14 centimeters. And what was more of a drag... my legs and a little bit of my left arm.

The cyst was on my spine, and that's why I have a valve in my back. And that doesn't stop me from doing [he coughs]... and that doesn't stop me from doing physical therapy, or other stuff ... I mean, here I lead a normal life.

I've had about seven or eight surgeries all over my body. Down here on my Achilles tendon, up here in my adductors, and I also had surgery on my neck ... I have a scar from it here, see? ... and then on my back. I mean, I've been gored more times than a bull fighter!

I came out walking after the first surgery they did on me. It was great. It went wonderfully! I said I went there.... I went for a check-up. Yes, yes this is fine. But later on I said: 'my legs don't support me anymore.' All of the weight of my back, it was on my back where I had the cyst and nobody knew what to do with me. And well then, I said: 'I'm going to go see my doctor, to have him look me over well and to have him do whatever he wants just as long as he doesn't leave me bedridden!' Well, you know what happened, at a young age, at 24, I was put in a wheelchair. But, oh well .. you have to live...

Work Experience

I work at the stand very happily, I work at my own pace. I go quickly but slowly ... because with the last semester I ended up stressed out. I got sick and everything. Because they made us rush for everything. And then I was in bed for an entire day and a half. On the third day I got up and they said to me: 'damn, you look quite well for someone who was in bed!' I said: 'yes ... yeah! I was really sick in bed, you know? I was in bed for a day and a half with a stomach virus like I had never had before [he is referring to a conversation that he had with another colleague from work]. 'But I mean, if I'm sick, I'm sick'. 'But you have to come to work!' And I said to him: 'Sick and all I have to go to work?' ... 'Juan I mean you have to understand that ...' 'Juan isn't bad but he isn't stupid. Don't take that the wrong way'. 'How am I not going to take that the wrong way?' Damn! They can end up saying some things that ... even the professionals: 'damn, how well you live! ... ' Because of that stomach virus I didn't go to work on those days.

At the stand I hand out information to everyone who goes by, to the professionals. My job is to be there from the morning, depending on the day, because if I have physical therapy at nine, I first have to go to physical therapy. And then perhaps I'm there from ten in the morning to five in the evening, taking a break to eat lunch and to do my exercises later on with another professor. And then if I don't have physical therapy, well then I work from nine to five in the evening, stopping to eat and stuff.

Yes, what I need there is a computer, I mean, to stop and say: 'at such and such a time you have such and such appointment...'

I give messages when, for example, the professionals don't come in to work. I'm very happy there.

Training

Well, in class I learn how to ... to ... to write, to count and to use a pen. I mean ... I'm pretty good at it. I do relatively well, I mean, because I do also make some mistakes, I mean ... I mean I'm not especially gifted.

I have classes at 1:30 p.m. There are eight of us and we have a good time.

In the workshops, my colleagues do everything: book binding, etc. they do a little bit of everything. And then people say that this isn't work ... Sometimes I go to the workshops, there is a schedule for the workshops. They are from nine to five with a break to eat and stuff.

I was always very athletic and I still am ... I really like soccer. Reading... I don't read that much; I mostly like to listen to music ... all types of music.

I like to watch television ... soccer games and to listen to the news.

The world is doing terribly ... because today, it was five years ago today when the Twin Towers happened. Those towers that they made...! Wow! That was certainly... There, they certainly had their ups and their downs. I like to watch the newscasts and when there are political debates on too.

Inner Life

Well... I used to go to mass, but not anymore. I used to go to mass because my girlfriend went to mass. When she died, I said: 'I'm not going anymore to mass'. But ... not because I don't want to, but because she died and since she went to mass, well then I said to her: 'I'll go with you'. And since she died, well I don't go anymore.

The church really doesn't work for me. Ever since she died I haven't gone, about four or five years ago. And she met me when I wasn't in a wheelchair. She knew me... well ... jumping around, playing soccer and all that stuff. And then suddenly it happened to me and she said to me: 'can I help you?' I said: 'but look how I am .. eh?' She said to me: 'I will help you but on the condition that you will love me.' I looked at myself and how I was ... and I said to myself: 'what do I want a girl for ... I can't walk or do anything .. Well, 'yes, yes I will love you very much' ... until ... well, ok ...

After she said that to me, she got really sick, I had to ... they had to admit her, I went to see her ... she survived the first bout, she was very courageous and she overcame it. But then with the second bout, she said: 'I can't! I can't any longer'. And she said to me: 'honey, I'm dying!' [he is visibly moved while he speaks]. It just made me ... Ay! I mean: 'my goodness!' Well, look, she was admitted into the hospital on a Friday, I don't remember if it was in the morning or the evening, and on Monday she died, she died.

Well... I said: 'it's better like this rather than having suffered. Better than having both she and I suffer.'

We argued like any other couple, we broke up a few times ... then after a couple days we would get back together, because that happens in all relationships. I met her here at the center, we would go out together on trips and ... we would say: 'good, if you love me, I love you and we are going to respect each other ...'

Because if she was sick and I was well I could help her ... then she wouldn't want that. And if I could help her, then the least she can do is not shut me out. You understand? Because she was sick with depression and stuff ... and I would go to help her and she would say no. That she didn't know me! I said: 'but come on ...' 'I don't know you and this and that!' I would say: 'we are going to respect each other ... to be careful'. Later, when she was no longer depressed and stuff ... 'Oh ... forgive me! Oh and ...and forget it and stuff.' She was ill, it wasn't a question of forcing her or hassling her. She was sick ... she started taking medicine and then it stopped ... but she had a very hard time, both she and I. Since I would see her like that, I would say: 'my goodness! This just isn't normal... it's not normal ...' That was some time before she died. And she would say to me, since she was suffering from heart disease ... she would say to me: 'I want to die.' She was sick, it was her heart and she would ... her hand ...when it got cold outside, her hands were very ... her fingers were ... her face and her hands would turn very purple. Oh! It made me so sad to see her.

I am very peaceful but society doesn't know how to appreciate the situation of a handicapped person. There are times when you say: 'go out in Madrid ... yes, What have I gotten myself into? If later you go and ask a favor, and there is someone who does it for you one, two and three times, then maybe on the fourth occasion he says: 'go down yourself and do it however you can.' People think that since we are here, like I say: 'we are isolated from society and that isn't so.'

Current Life

On any given day I go to bed around ten, ten thirty, eleven, it depends on how tired I am. If there is a soccer game on television that I like, then I stay up to watch it ... but

during the week I get up every day at seven in the morning. The night aid comes to turn me over and then later on another aid comes to get me up out of bed, his name is Estefan. And he comes and gets me up. He gets me up, he puts me into the bathroom, I do my business, go to the bathroom and whatnot ... depending on the day and then he bathes me and stuff ... Then he gets me dressed and at about two or three minutes to nine I'm already out the door. Later on I have a glass of milk ... or whatever I find to drink in the house and ... and then I've gotten everything taken care of. Later at midday I do my job at the stand and I do my work.

When I have physical therapy, they move my legs and my arms and they also stand me up so that I'm not sitting down all day long. And when I go to the bathroom, I try to do so standing up ... and I can use my hands and stuff. They have to hold me up so that I don't fall backwards and stuff, but I get along.

I also have a private physical therapist. Besides the fact that I go with Carlos, normally on Thursdays, on Tuesdays I go with Carlos at nine o'clock ... I do exercises from nine to ten, and then later on I go to my place of work [he means the stand] and on other days I go with Tamit so that he can stretch out my legs a little and he stands me up a little on my feet. And it's very good [he says with satisfaction]. And above all, I have a great time ... working and knowing that I have people who love me.

So that I don't get bored, I do a lot of things. We never get overwhelmed by being in here too much because, for example, on the weekends ... we go to Madrid. The other day we went with X [he is referring to one of the aids] to the Sports Center [Palacio de los Deportes] to see a concert. On the weekends, here ... well ... when it's nice outside, we go to the Sierra mountains. I've been in the center of the earth, up there ... you can't imagine what a feeling it is! And this summer I was in Riaza ... in the province of Segovia. Last month, two months ago, I went on vacation. We stayed in a hostel. And I had a great time ... a great time! Because I was in the pool and that's what I wanted to do. I don't want the beach or anything of the sort ... I want the pool! And there you are relaxed. And we've gone on a lot of trips. We've been to Pinilla, up there... And I went on a chairlift and I had never been on one before! I looked down and I said: 'Oh my goodness! If this things falls down ... We are going to crash!' Since we went with the aid from our school he said: 'don't you worry, nothing is going to happen to you here'. I was there for a month, relaxed, going on day trips all around, around the town ... and then we came back. I always come back very happy from camp.

In the house I help with whatever I can .. well, I tell everybody what's going on and I'm very well cared for. And in fact, I am indeed. I'm very happy and what more could one want? Well... people come and they say: 'Oh, the guy in the wheelchair!' The guy in the wheelchair can show you what he can do. Because they say: 'damn ... he just can't do anything and this and that!' I mean! ... Have you seen me work in order to be able to say that I can't do anything?' I mean it's really nice to come and say: 'because you are in a wheelchair so you are useless.' Well ... I am worth something and I can do things! Well ... man, you can't ask me to step up onto the curb, and you can't ask me to get up out of my wheelchair or to get into a van. You can't ask me to pilot an airplane. You understand? I mean that is very nice to say, but I've been ... I've been at the point of saying: 'let them do everything for me and then'...

Vision for the Future

The first day that I was in a wheelchair, I said: 'I'm going to stay in the house and not go out.' Because I saw myself as being helpless. I saw myself as saying: 'good ... now let them do everything for me. Let them shower me, let them dress me, let them put me in the bathroom, let them wash me and let them do everything...' And then, later on in

the street, I said: 'ladies and gentlemen, that's it! That's enough! I myself, will cook it and eat it. If they have to help me... then they have to help me. If they don't want to help me, then they won't help me... but I'm going to do what I can. First and foremost, I have a lot of dreams. [he breathes in deeply] .. the dream that I have... if it were possible ... would be for the doctor to tell me: 'I will operate on you and in a year you'll be walking.' I would right now grab that chair right from where it is and I'd put it out on the street. I would do it... ladies and gentlemen, I'd walk again! But it's very hard. There are a lot of people who are in wheelchairs and there are people a lot worse off than I.

Comments on Victor's Story

Victor's story is touching; he is a fighter, he is courageous. Despite all of the crises that he has endured, orphaned by his father and mother, no contact whatsoever with his closest family members (sisters) he feels taken care of in the institution and believes that his current situation is not the worst, stating that there are handicaps worse than his.

He entered the center as a teenager, with a diagnosis of a slight intellectual disability, but his life projects were cut short in the past as a result of the emergence of a degenerative disease, to which he refers when he talks about the "cist"; this illness is progressive and, according to data taken from the self-assessment form, it comes from the following (provided by one of the program officers): "Diagnosis: at 20 years of age, the emergence of a degenerative disease in the spinal cord. Left dorsal-lumbar scoliosis, spastic paraparesia and right hemiplegia."¹³

In recent years, the disease has evolved, progressing on a yearly basis, which has led to his increased need for contact with and dependency on the physical therapists. He receives additional physical therapy for his treatment than what is usually provided by the center.

As he has a mobility dysfunction, Victor depends on the help of others daily: to get up out of bed, bathe and dress himself. The attention he receives must be provided and monitored continuously, even when he is in bed, as he needs to have his position changed in order to prevent other types of ailments.

As a result of the hemiplegia, his torso appears visibly affected, showing little mobility and dexterity in his arms and hands, especially on his right lateral side. Nevertheless, Victor views life optimistically and maintains positive emotional defences that shelter him intellectually and allow him to escape from any future reality.

Fear of the illness, its progressive deterioration, becoming bedridden and death (information provided by an aid) lead him to develop evasive thoughts. Such defence mechanism are extremely positive, since they serve as preventive brakes against processes that involve depersonalization and emotional problems related to a person's adjustment to his/her new reality.

¹³ Definition of Spastic Paraparesia: loss of strength, without going as far as being paralysis, in both lower limbs. Source: Glossary, www.discapnet.es.

Another highly significant indicator is his current state of “activity”; that is, holding a job, one that is within the center itself. The job gives him energy, autonomy and self-worth, as he sees himself as being productive and capable of taking on responsibilities.

Victor is aware that the support he receives from the institution is of the utmost importance. He considers it his home, in the broadest sense of the word. The facility, professionals, nuns and fellow residents, make him feel as if he were an integral part of it all, carrying out an important role among them. It is there where Victor has his social ties because it provides everything in terms of his emotional life; he is able to give and receive affection, he can get angry or be friendly, he can talk and negotiate. He is considered the “boss” by his fellow residents, he knows everything about his surroundings, as he is a well-known and highly-valued member of the group.

In legal terms, he is not incapacitated; in fact, he makes judgments and has opinions on politics and communal living and, when the time arises, he will take part in voting when there are elections.

His intellectual disability is minimal, his greatest degree of difficulty is of a physical nature. His physical dependency is taken care of by the institution, both in terms of medical care and therapy, as well as in regards to his educational and emotional needs.

Assessing his current situation, and keeping in mind ICF’s criteria, Victor’s degree of dependency is severe, and complete in nature. His high appreciation for life, clinging to it with all of his might, is an admirable example of his dexterity, social skills and inner resources that guarantee him a healthy today; however, given his degenerative disease, it is difficult to foresee a very positive future for him.

MARÍA JESÚS AND THE SPAGHETTI

Presentation

María Jesús is 51 years old and she was diagnosed with Down Syndrome.¹⁴ She was orphaned by both her father and her mother when she was very young. She has two brothers that visit and take her on vacation. She is very involved at the residence facility where she lives and she goes to a workshop every day.

Familial Context

I’m 51 years old. Well... I’ve been here for many years now, they put me here in this center, my father and my mother. They put me here. I had a father and a mother but both of them died. I have two brothers. We were born in Aranjuez. I don’t remember

¹⁴ Down Syndrome: A congenital disorder in which there are three copies of chromosome 21 instead of two (also called Trisomy 21). Mothers of an advanced age are more likely to have a child with this disorder. It produces a mental retardation that ranges from slight to severe and is also associated with specific physical characteristics including abnormal height; a rounded, brachycephalic skull with flattened occipital region; almond-shaped eyes; a broad, flattened bridge of the nose; an open mouth and enlarged fissured tongue; broad hands with stubby fingers; and often a single “simian” palmar crease. Sometimes congenital heart defects are detected in the area that separates the left side of the heart from the right. In some cases, the onset of a premature kind of dementia like Alzheimer’s Disease emerges around the age of 40. Source: Glossary, www.discapnet.es.

when my parents died, but they died a long time ago.
My brothers are married, the older one and the younger one. I have nieces and nephews. My older brother had five and the younger one had three. One of them is married ... he got married a little while ago, the younger one and the girl. My brothers come to get me. My older brother and the younger one usually come.
There are times during Easter week that they take turns and divide up the time, I'm divided up ... Once, with my older brother and the next time with the younger one.

Social Context

I have friends at the center. Well... there is Magdalena, Lola, Carmen ... the one that I get along with the best, I get along really well with her! That one, who's a little fat, and then there is Angelines too, another fat one. And Susana and the other Susana. There are two Susanas! [she names each one of the other women in her unit].
Sometimes I get angry, but then we are friends again. Yes! Well, later on I get over it.
With the nuns ... well, it's good, but then later not too much, not so much.

Health

Nothing hurts me. I'm fine. I don't take any medication.

Work Experience

Well ... I work, I'm in a workshop. I'm working with my boss whose name is Tani ... I don't know if you know him. His real name is X [she gives the aid's name] but I call him Tani.
Well... jobs, well, he usually gets them, they are jobs and he gives them to us to work on. Well... we make a lot of things, we make colognes, then we make men's ties, baby sheets, and then there are the caps. Yes! Then they are put inside something so that inside, something is put inside the cap ... and we do this by hand. And my coworker pounds them in, pushing it farther in so that it fits well. And that's it, we are going to do that tomorrow. I really like to work.

Training

To school... me there.... No! I don't remember if I went to school when I was a little girl.
I don't like to add and subtract. I like to cook! The garbanzo bean stew [cocido] and lentil stew are my most favorite dishes. Oh! And stewed potatoes! Well... I don't like sweets very much; I like salty foods rather than sweet ones. I like to cook but the nuns don't let me ... if they let me... then...

Inner Life

For me....Yes I like church! You see I sing there. I'm in the choir there, in a group, a choir group. I like to sing things for mass. There are some things that I don't know [she gets a little tense, trying to remember]. I can't remember right now.

Current Life

Well, first I shower and then after I shower I put on my pajamas, my robe and I wait for the others ... first they shower. Then, they do of course! They all shower ... well, I mop the hallway. Once I'm showered, I go and I mop the hallway.
And then I go back to my room ... you've already seen my room and then later we wait

until it's dinnertime. And then we have dinner ... and then since I have a television... well I wait, I put on my TV and I watch TV until the sister counts the others. Then, I go out and I stay with the sister and another girl to watch TV [she refers to the one in the living room of her residence hall] until about 11 or so.

And then we go to bed, then I get up again, I get up. First, the sister goes, she leaves us in our beds, and she goes and then later ... You see she goes to pray, because she is a nun! She goes and prays the 'Our Father' and stuff ... and then she comes down. After, she wakes us up and then we go and we have breakfast and then I take a sandwich with me... the sister makes me the sandwich.

We go to the workshop to work, and then there is an hour-long break to eat my sandwich. We work until two, until it's lunchtime. And then after lunch, there is another break, which is for recess in the street; we go out to the street. I have a coffee until three and then I go back to the workshop.

We are there until five in the evening.

This summer we went to a camp in Tarragona. I don't know where ... I don't remember. And that's where ... since it wasn't my older brother's turn, it was my little brother's turn and he went to pick me up in the Plaza of Castilla and then I went with them [she is referring to the day that she came back from camp].

I like to watch television in my room after the workshop. I like everything.

I like to go out to the festivals, some have just started here in Majadahonda because the ones in Pozuelo already ended.

Vision for the Future

What I don't like and what I wouldn't like is that .. eh, eh! [she gets a little nervous but wants to talk]. Is that, is that in the cafeteria, they take food away from me. Today there was spaghetti and tomato sauce ... well they say: 'that I'm not going to eat it with tomato sauce' [she says this angrily]. And that was a lie! X [she names one of the aids] ... well, he is really very tall, today he didn't give me spaghetti and tomato sauce. I took them myself ... and I walked away ... I don't want them! Yeah...of course! They don't let me eat what I want to eat. No, no! Tomato sauce isn't bad for me! No! To the contrary! They tell me that I have to follow a diet. That I have this and that. But I don't! I can eat everything. What happens is that X doesn't want to give me those because he thinks that I am going to get sick. I say to him: 'be very careful ... you are not going to play games with me!' Well yes, You get out of here! You get out of the cafeteria!

Comments on María Jesús' Story

Down Syndrome is the most common and easiest to recognize of all of the conditions associated with mental handicaps.¹⁵ María Jesús shows two of the main difficulties in people who suffer from Down Syndrome: the presence of a delay in her cognitive age development as compared to her chronological age and the slowness in her cognitive capacity, her reactions, as well as her way of acquiring and processing information.

¹⁵ This involves a congenital variation that occurs as a result of an abnormality in one's chromosomes: for some unexplainable reason, a deviation in the development of cells leads to the production of 47 chromosomes, instead of the 46 that are considered normal. The additional chromosome completely changes the organized development of the body and the brain. María Jesús shows physical characteristics that are common in individuals with this syndrome, such as a small head, almond-shaped eyes, small and flattened nose and large tongue.

Difficulties are also observed in regards to the development of the following processes: attention mechanisms, alertness, attitudes for initiative; expression of her temperament, behavior and social skills; short-term and long-term memory processes; correlation mechanisms, analysis, mathematical calculations and abstract thought; and expressive language processes.

Research carried out in this field has proven that children with Down Syndrome can acquire skills for self-care, and that their learning level usually oscillates both in terms of mental development and intellectual capacity. With regard to María Jesús, there is a lack of knowledge about her childhood and it is not known if she attended school; however, it is true that she does not know how to read, write or calculate basic mathematical equations.

María Jesús, despite her age, might need some type of educational opportunity; trying to learn some basic concepts of instrumental subjects so that she might be able to be more autonomous in those areas. She does not understand the value of money; she only knows that if she puts a big coin in the machine she can get a cup of coffee.

In regards to her relationships, she does not leave the facility often and, when she goes out with her brothers on an occasional weekend, she is not always comfortable with her extended family: sisters-in-law, nieces and nephews. However, she loves her brothers very much and her relationship with them is good. At the center, she is well integrated with the other residents, and while sometimes there are disputes or conflicts that arise in the context of communal living, they are passing or short-lived. She has managed to develop strategies that make it possible for her to achieve her goals; for instance: she loves coffee and Coke, and she likes to be helpful to others to get money. She seeks company to ask for and achieve what she wants.

Another aspect on which María Jesús would need to work harder relates to her domestic life; she takes on a task in her residential unit: mopping the hallway, which she does several times a day. It would be productive to support the interest she has expressed regarding the kitchen and cooking.

Her job in the workshop and her participation in the church choir are positive mechanisms, which are good for her self-esteem. María Jesús is skillful at her job; she can carry it out successfully and is capable of taking on responsibilities, even though her pace of work is very slow.

Assessing her years of institutionalization, her chronological age and her diagnosis, her degrees of dependency are moderate to severe, since she requires continuously supervised care and attention on a daily basis.

BEATRIZ AND HER DOLLS

Presentation

Beatriz is 27 years old. The number of years she has been institutionalized at the center could not be confirmed. She has parents and two siblings. She goes almost every

weekend to be with her family and returns to the center on Mondays. Her diagnosis is *Intellectual Disability due to Hypoxic Ischemic Encephalopathy*.¹⁶ She attends the center's occupational service workshops.

Observation: Below is a literal transcript of the entire interview with Beatriz because, due to her problems, it was not possible to assess certain contexts and life experiences.

Interview

I: You were telling me Beatriz that you are 27 years old, right?

B: Yes.

I: Tell me, what do you do during the day from the time you get up until you go to bed?

B: I sleep.

I: And after you sleep ... in the morning?

B: I get up. I have breakfast. Other things.

I: What are those other things?

B: I work. I like Fridays.

I: You like Fridays.

B: Yes, because I go home.

I: Do you like to go home? Do you go home every weekend, and this Friday?

B: This Friday.

I: This Friday. And who is at your home?

B: Mom. Dad and Pedro and Rosa.

I: Pedro and Rosa, are they your brother and sister?

B: Yes.

I: Are they older or younger than you?

B: Older.

I: Are you the youngest?

B: Yes.

I: How many years have you been living at the center?

B: What?

I: How many years have you been living here...?

B: From Monday to Friday.

I: And the weekends?

B: I leave.

I: And here at the center, do you go to the workshop? Do you go to school? What do you do?

B: I go to the workshop with Josefa.

I: What do you do in the workshop?

B: I work hard. I don't know, I work, I draw, all of that stuff...

I: Wow, that's great! You work and you draw. And do you go to school?

B: Yes.

I: And what do you learn at school? For example, adding...

B: Yes, yes adding ... yes. Adding, yes.

I: And do you like to read?

B: Yes. A lot of other things.

I: Let's see, tell me, for example... I'll listen to you.

B: Reading, writing, everything. Painting, coloring, everything, resting, everything. I like everything. I like almost everything.

¹⁶ Hypoxic Ischemic Encephalopathy: A syndrome characterized by various degrees of neurological damage as a result of severe or prolonged perinatal, inadequate supply of oxygen.

I: Did you go on vacation this summer?

B: Yes.

I: Where did you go?

B: Ayllón.

I: And where is that?

B: Very far away. Out there where Riaza is.

I: Ah! How long were you on vacation for?

B: Fifteen days.

I: Who did you go on vacation with?

B: With the aids.

I: With aids from the center?

B: Yes.

I: And what did you do while you were on vacation? Tell me...

B: Let's see, one thing. On vacation, riding a bike, playing paddle, a lot of things.

I: And did you go to the pool?

B: Yes, lots of things.

I: But, what are all of these 'lots of things'?

B: Playing tennis, lots of things.

I: Do you like to watch television?

B: Yes, [she talks through clenched teeth, quickly, and it cannot be understood] On Friday.

I: Excuse me?

B: I might stay on Friday.

I: You might stay on Friday?

B: The doctor gives me pills and I don't want them. You see I have... well, I wanted to go on Friday.

I: Tell me, is there something special happening at your house on Friday?

B: I want to see my mother.

I: We were talking about what you like to watch on television... Were you telling me that you like to watch television?

B: Yes.

I: What programs do you like to watch?

B: For example: Ankawa. Ankawa.

I: Very good... Anything else?

B: Neighborhood Cinema. A lot of things. The Simpsons. A lot of things.

I: Tell me, who lives in your residence hall? Who are the others here with you?

B: Juana, Angélica, María Elena, [she talks to herself, quickly, it cannot be understood] Marta.

I: Who do you get along with the best?

B: With Angélica.

I: And who do you get along with the worst?

B: With Saleta.

I: Beatriz... Do you ever get angry, what would make you get mad at people?

B: Another thing and I get angry. When they bother me. I don't like that.

I: Yes... And with your brother and sister? How do you get along with them?

B: Very well. Sometimes they get mad. I make them angry... [she says something to herself] That depends on them.

I: And with your parents? How do you get along with them?

B: Very well too.

I: Were you born here in Madrid or in another province?

B: I was born in Pozuelo [she says something that has nothing to do with what we are talking about but it is understandable] Pilar.

I: Who is Pilar?

B: She tells me to leave.

I: Pilar... Is that another one of your friends here, is she an aid?

B: No, the psychologist, in the end you will stay on Friday... that is true, on Friday I might leave.

I: Will you come back on Monday?

B: No, I'm going to stay there bored...

I: What do you do here so that you don't get bored?

B: Well... I like lots of things at my house. I like this. I like to have fun with my family. I love it. I am, I mean, a person, I mean... I don't know why.

I: What types of things do you do with your family?

B: Yes, for example, my father goes out.... He takes me out to the street. With my friends, my mother goes out to do the shopping. I like that. Oh my goodness, she comes... [she talks quickly and what she says cannot be understood] back home, I like that.

I: At the residence hall... Do you like to do household things?

B: I like to do a lot of things. I've already gone, a week, on a Tuesday. But now when Christmas comes, yes I ... I like to cook, it makes me happy.

I: So you like to cook?

B: Yes.

I: That's great! Tell me what you like to make.

B: To make a circle, another circle, one small, another one large.

I: What food do you like to cook?

B: For my mouse Pérez, a meatball. I cook for him, for the doll.

I: Ah! For the doll. You cook for the doll!

B: You see, he makes a fuss and he complains... Mom, I don't like this, I don't want this. And sometimes I give him the things and he says: 'I don't like it.' Yesterday, my mother, how she got with my brother! He didn't want to eat.

I: He didn't want to.

B: I know!

I: Do you have a lot of dolls?

B: Yes.

I: Let's see, tell me about your dolls.

B: Pérez the Mouse, lots of them, Robin, I have them all, all of them, all of them.

I: Do you really like dolls?

B: Aha! I love them.

I: Do you have a lot of dolls in your bedroom?

B: I have the dolls, because without them... [she is silent]

I: So, you cook for your dolls. What else do you do for them?

B: Pérez the Mouse tells me: 'Mom, I don't want this.' Well no, 'you are going to eat it. It's a stew that I've made for you. The food is not going to be thrown away, it must be eaten. You won't do anything until you finish what is on your plate.' Well no, it cannot be left. I don't care... I love to cook and to wash the dishes. I love it!

I: And do you help your mother prepare the meals when you are at home?

B: Sometimes I do. You know... my mother makes me what I least like, and not enough salt... you see, the food that my sister makes for me... she gives it to me all day long and to top it all off, she doesn't like meat, only a little salt, red salt and it made me vomit, and I got really sick. I mean, I ...

I: Beatriz... Do you like to read?

B: Books are like children, like children who fight about any little thing, fighting with each other, hitting and killing one another (...) [what she says cannot be understood] (...) on Saturday at my house [she speaks in an angry tone] (...) it hurt me, it hurt me and I say 'if it were up to me (...) capable of taking it away from her' (...) well if that's the way it's going to be.... That's it, we're leaving! Well no (...) because it is for the two of you, that is, you have one and you have the other (...) that's how it goes (...) (...) a friend (...) I had a fight.

I: It seems like you really like the topic of dolls, right?

B: Yes, because if you have a doll and then to top it all off they leave you without that doll (...) that doll and that's it, the end (...) my father (...) has double (...) and dad says (...) furiously (...) and I ran off crying. Mom (...) on Friday. What does it matter. And nothing... (...) Well, that's it, end of story.

I: Tell me Beatriz... Does anything worry you today?

B: Well at least I worry about another person from here bothering me and I don't like that. That's terrible. Let's see, what do you want? Nothing, just this. Virgin Mary! [she sings this].

I: Oh, so you like to sing?

B: Of course, and nothing to do and all (...) it doesn't matter. Well (...) six thirty and I don't know what time it is now. I don't have the time, you do, but I don't have the time.

I: Yes, I have the time but let's talk a little more and then you can go, all right?

B: Ok. One day, look, I'm going to tell you something (...) we went to my sister's house. I went to my sister's house because (...) and it didn't end and all. Wow, what a pretty house you have! But how pretty! And I say to her: and Jama? And the baby? The baby (...) had... Well and that's it (...) [her sister is married and has a little girl].

B: Well, as long as nobody bothers me I'm fine. If they are bothering and joking around with me all day long, I don't like it (...) the jokes, I just don't feel like it (...) In order to not mess everything up, I prefer (...) and then (...)

I: Who are the most important people for you?

B: For example Rosa, Juan Pedro, Dad and Mom [she is referring to her family].

I: Rosa is your mother's name.

B: (...) who is still very tiny.

I: Who is very tiny?

B: Someone whose name is Beatriz like me. She is a baby. She is like a doll but with skin.

I: Your family, do they come to visit you at the center?

B: My sister Rosa, my sister comes to visit me (...) ah, this is my daughter. Because (...) introducing my whole family. I mean, that is why... but oh well (...).

I: Thank you Beatriz. We are going to end the interview now, ok?

B: Ok.

Comments on Beatriz's Story

The purpose of providing the complete transcript of the interview is to show the difficulties related to the following aspects: the inconsistency of her discourse, the lack of appropriateness and logic in her responses and a progressive decline in her language, which in turn affected negatively her thoughts in terms of producing messages. Beatriz's diagnosis, according to the center, is the following: "Intellectual Disability due to Hypoxic Ischemic Encephalopathy. Convulsive crises with tonic and clonic movements. She is medicated for epilepsy and she is given tranquilizers, birth control and antipsychotic drugs.

Because of these manifestations, we have important gaps that we would need to fill in before reconstruction her life story; we also do not have any information about her special nature, environment or other contexts.

With respect to her integration at the center, Beatriz does not show any major difficulties: she maintains good relationships with the other residents at the facility, although she occasionally has disputes and conflicts.

Beatriz maintains close family contacts, leaving the center every weekend to spend it with her family. She returns to the center on Mondays. Her emotional relationships with her parents are positive, as is the one she has with her older sister who is married and has a little girl. Her relationship with her brother is more tense.

She participates in the occupational workshop and in the institution's special education program. Beatriz's limitations are more of a neurological and mental nature, which involve and affect the other areas of her autonomy and dependency (information that has been determined from the self-assessment form). Therefore, her current degree of dependency is deemed moderate to severe.

ANTONIO, DEDICATION TO HIS JOB

Presentation

Antonio is 29 years old. He has lived with one of his brothers in the Foundation for a very long time. He is very shy and does not go into great detail with his comments. His diagnosis is *Intellectual Disability due to Fetal Alcohol Syndrome*.¹⁷ Currently, he works as a gardener outside of the center.

Familial Context

I have lived here for a long time. I had a father and a mother but they have both died. There are three of us: me, my brother Martín and my brother Carlos. The oldest is my brother Martín, and I'm in the middle. Sometimes, sometimes my aunts come. My aunts sometimes, since they are... Yes, well... we spend Christmas Eve with my family [he is referring to himself and his brother] and New Year's Eve we are here. They are good [he is referring to his aunts]. I have cousins, and I get on well with them. I was born in X [a town in the province of Segovia]. My parents are also from there. I was in a relationship, but I broke up with her. There's no chance of reconciliation because that girl was, she was annoying. Yeah, because she would always call me, and call and hang up [he is referring to his mobile phone], call and hang up and for me to answer her... I won't answer. She's at the center, but she goes with her family. She works here but then she leaves when the work day is over; she goes to her house.

¹⁷ Fetal Alcohol Syndrome is a characteristic model of congenital anomalies (present at birth) that are produced as a result of the mother's use of alcohol during pregnancy. The range and severity of the symptoms and of the manifestations associated with it can be extremely varied from one case to another. However, the illness can be characterized by prenatal and post-natal (before and after birth) delays in growth, craniofacial malformations, including microcephalia (abnormally small head), brain anomalies, heart defects and other physical changes.

Social Context

I live here... in the boys' house. Well, I live with ... José, me, my brother Martín and Julián. There are four of us. Great! Great! [he is referring to the fact that he gets along great with them]. Well, my caregiver is X [he names the aid].
I went on vacation for fifteen days to Tarragona, eh! In the country of Tarragona. Yeah, to a camp. I went to the beach, to visit all of Tarragona.
I go out very little, but I go out on the weekends [he means that he goes out in Madrid]. Sometimes, I go to Aluche, to Majadahonda, to the Puerta del Sol... you know, around, around...!

Health

No, no health problems. Yessssss! I have hearing aids.
Regarding my sight.... A short time ago, eh! A short time ago my eyes went. Yes! I bought glasses and I wear them [even though at the time of the interview he was not wearing them].
I don't take any medication.

Work Experience

I work in gardening but in Mercamadrid [he says this enthusiastically].
I work from seven until, until three o'clock... I get out at three. Well... I do the cleaning and I cut the hedges. My boss, X [he names his boss], good. I earn well... 200 and something, I don't really remember that well, I'm not very good with money. I keep my money in the bank, and I buy myself clothes or whatever I need.
I go to bed early... of course! I have to get up really early, at four o'clock in the morning. I'd like to stay in this same job, I like the work. I've been doing it since July or August... I don't remember.
I have some co-workers and I get along well with them.

Training

To school, no, no! [he says this as if he is unsure about the answer]. I don't remember.
Reading... I've never read... but I do like it. Maybe I went to school when I was a little boy. You see I don't really remember much right now.
I can travel on the bus and the metro ... yes, yes. When I don't know a place, or a street well then I ask.
Before going to work ... I was in a course in Las Rozas, a little course in Las Rozas. It was about gardening too. It was a course on clovers.

Inner Life

Well... I'm nice. Well... I'm mentally handicapped, I don't know... [he smiles timidly]. Sometimes I get angry, but not much... What am I like? [he shrugs his shoulders]. When I feel bad... well, I stop to think about what I've done wrong.

Current Life

Every day, I get up at 4 in the morning even though I start work at seven. Well, I have to go from here to Moncloa, and then from Moncloa to Legazpi, and then in Legazpi I catch another one, a bus all the way till the end of the line to Mercamadrid. Every day! Monday through Friday. Not on Saturdays or Sundays.
When I get back after work ... well, I rest. I watch TV ... well, I watch a little bit of everything. What I most like is... well, that one... it's Cuéntame, and sometimes I watch some series and movies.

We don't prepare our own meals. The cooks from the other side [he is referring to the kitchen that is adjacent to the center's cafeteria]. At eight thirty ... we go to pick it up and we eat it here [he is referring to his unit].

I listen to the radio, the Cadena Dial, Radio Olé... the one I like the most is the Radio Olé station. Sometimes, they put on things like rumbas, sevillanas and some fun ones. Sometimes I play soccer and basketball.

Well, what worries me... well, I worry because I don't want to leave the center, the house. I really like to be here.

Vision for the Future

I haven't thought about that yet. Yes, yes! In five or ten years from now I would like to live in a house, with my brother [he is referring to going to live in another place, outside of the center].

Comments on Antonio's Story

In the reconstruction that Antonio makes, we observe several adaptive indicators that are highly significant. Despite his shyness and his intellectual deficit, he has managed to overcome socio-cultural barriers, integrating himself into the labor market. He currently holds a job that requires him to get up very early and make a complex commute on public transportation, proving he is capable of being responsible for following a schedule, taking on duties and solving problems.

He lives in the "Boys' House", a special unit of the institution where the most autonomous residents live together, and he maintains a healthy interaction with his fellow residents, aids and other professionals.

With respect to his childhood, Antonio does not remember many things about his circumstances. Nevertheless, one of the aids provided the following information: when he was a little boy, Antonio lived for a few years in France with one of his aunts and he came to Spain speaking French. It is not known whether he received formal education at any given time, but he does recognize the alphabet and he can read and write. In regards to his family, it is known that his father died and that his mother abandoned him and his brothers. They are three brothers, and Antonio is in the middle. All three brothers share the same diagnosis: Intellectual Disability due to Fetal Alcohol Syndrome. Two of the brothers live in the Foundation while the current whereabouts of the youngest brother is unknown.

Antonio is very close to his older brother: in all of his plans to go out of the center and in the day-to-day communal living he needs his brother's emotional presence. He even stated that in a few years he would like to live in his own house with his brother. In addition, as background information the aid informed us that both brothers have a house in their ownership that is not currently lived in by anyone, which they had received in an inheritance. Antonio maintains a good relationship with his maternal family, his aunts visit him often and they take him out.

Antonio shows some important social abilities, which is what led the Foundation to organize a position for him in an adapted job. His salary is actually higher than what he says it is because he gets confused when faced with large quantities of money. He needs more support in this area so that he can acquire other skills. Moreover, he would gain greater

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autonomy if he had the chance to learn to develop domestic life activities: for instance, learning how to cook, clean, do the laundry and ironing, etc.

His health is stable; he does not require any kind of medication; he has visual and hearing problems, but he has glasses and hearing aids. Currently, his degree of dependency is slight.

PEOPLE WITH ACQUIRED PHYSICAL DISABILITIES

The World Health Organization has decided to completely abandon its use of the term “handicapped” due to its negative connotation and it has turned to the term disability as a comprehensive, generic term. The International Classification of Functioning, Disability and Health (ICF) has been established to assess and measure disabilities in scientific, clinical, administrative and social contexts.

A physical disability is complex and even multidimensional, as it not only refers to a series of specific health problems in a person but also to that person’s interaction with his/her surroundings, i.e. the environmental and social barriers that determine one’s state of health or deficiency. For this reason, it is always necessary to identify the “main problems of the disability,” whether they are found in the environment due to the existence of a barrier or because of a lack of assistance, if it is because of the person’s limited capacity, or whether it is due to a combination of factors.

In the case of a physical disability, one of the key elements is mobility. The WHO defines mobility as the activities that a person carries out to change or maintain a bodily position or placement; upon taking, moving or using objects, walking, moving or displacing oneself using a means of transportation. The *technical aids* (helpful products and technologies) are instruments that improve a person with a disability to function.

Consequently, the time at which a person receives his/her own orthotics is very significant, as those devices represent the taking on of a new reality: a wheelchair, body braces, and other pieces of equipment are going, as of this moment, to form part of his/her body and, therefore, of his/her life. This situation produces different reactions: anger, depression, rejection, deception because of the material’s quality or because of how difficult it may be to use it ... or it may generate a sensation of relief from having an aid that will make his/her autonomy possible. The reactions depend on each individual and on the way in which these technical aids have been provided, as well as the image that each individual had of him/herself before the need arose for such technical aids.

The assessment teams for situations of dependency due to mobility difficulties, along with the dependent people themselves and their families are the parties responsible, in every case, for determining the service or services that they consider the most appropriate: Tele-Assistance, Home Care Services, Attention in Day Centers, Services for Personal Autonomy, Residential Services, Technical Aids, Help for Home Adaptation and Accessibility, etc.¹⁸

¹⁸ The assessment and degree of the dependency, while it may be narrowly related to the amount of help that is provided and the work that is expected, should not be considered on equal footings. Some concepts should be considered differently; for instance on the one hand, dependency, as a concrete fact of needing the help of another person for certain life activities; and on the other hand, intellectual autonomy, as an abstract faculty of decision-making in regards to the management and the self-determination of life itself (regardless of having a disability or not or of situations of dependency on another person).

Interviews carried out at the Spanish Association for Multiple Sclerosis Madrid

(ADEMM)

The ADEMM is a non-profit, public use entity that brings together people who are affected by this illness, as well as their families. It is a country-wide association formed by local, provincial and autonomous community associations. Currently, it has more than 1,400 partners in the Community of Madrid. Many health professionals collaborate periodically or regularly with the association. Its main objectives are to:

- ❏ Bring together people with Multiple Sclerosis (MS) and build a human and social support system for them and their families.
- ❏ Provide information on MS to those affected by it, their families and professionals that ask for it.
- ❏ Raise awareness among public opinion and governmental administrations.
- ❏ Improve the quality of service, as well as the amount of available resources for people that suffer from MS.
- ❏ Promote the creation of services for comprehensive rehabilitation, support, maintenance, etc. throughout Spain.
- ❏ Promote systems of help for its associates in order to bring about their social integration.
- ❏ Inform and advise on all of the possible services and aid that the affected person and his/her family will require.

ADEMM's main activities focus on comprehensive assistance; through the following services:

- ❏ Social and assistance centers: Day Center.
- ❏ Home Assistance.
- ❏ A "bank" for technical aids.
- ❏ Informational activities: Center for Information and Consultation, information via the telephone, through writing, publications, informational sessions, colloquiums, training of volunteers.
- ❏ Activities with Professionals: Training courses related to MS (for physical therapists, health care aids, psychologists, occupational therapists, speech therapists and social workers. Scholarships for professionals in the field of MS.

Observations: Of the four cases presented below, three are about people with Multiple Sclerosis¹⁹ and one case involves a person with Cerebral Palsy, who is a beneficiary of the Social and Assistance Service of the Day Center.

¹⁹ Multiple Sclerosis (MS) is a disease of the central nervous system that affects the brain's capacity to control certain functions like: speech, sight, movement, etc. It is referred to as multiple because it affects the brain and the spinal cord in a dispersed manner; and as sclerosis because it leads to the formation of patches of scar tissue called plaques on the damaged areas of the nervous system. The healthy neurons are insulated by a substance called myelin, which isolates and protects them and helps electrical signals pass quickly and smoothly between the brain and the rest of the body. In MS, the myelin is destroyed in certain areas, and is substituted with hardened fiber (plaques) that disrupt and can even block the transmission of the signals. Most people have their first symptoms between the ages of 20 and 40; symptoms rarely begin before 15 or after 60. Women are more likely to be affected by the disease than men. The symptoms vary greatly among individuals and in a single person at different times. The following symptoms may indicate the existence of MS, although

ANGÉLICA AND MR. ROCA

Presentation

Angélica is 59 years old. She is divorced and lives with one of her children. She spends a lot of time alone at home. She has three children and one grandson, but she is not with them as much as she would like. She was diagnosed with Multiple Sclerosis in 2003. Currently, she is in a wheelchair and she goes to the Day Center daily. She receives a non-contributing pension and economic help from her children.

Familial Context

I have three children. I have a daughter who has a three year old little boy and my other son also has a girlfriend. The only one that lives with me is my eldest son and he works and comes home late, of course... well look, I've had the disease but I've had to deal with it all on my own because I was separated from my husband. Because of that separation I stayed at home because I was already walking a little badly because of my legs. And I didn't want the people to say: 'ay... well for them to look at me as if they pitied me', or for them to say 'poor thing'. I didn't want the people to have pity on me. And so I stayed inside my house for seven years. That was seven years! And then I got agoraphobia. And later I was terrified to leave the house. My children forced me ... they wanted to take me out of the house, they would take me down to the front door of the building and then nothing. They had to take me back upstairs, back home because I was incapable of leaving. So then I stayed in my house for seven years. And of course, it's known that I would have a new flare-up every once in a while, but I didn't think that it was anything like this. Well, it's about walking, I don't walk well, because I don't walk. I walk from the living room to the kitchen, from the kitchen to the living room... I would sit. Then I found that I was tired, I would take vitamins because I told myself it was spring asthenia, but...oh no! It was this. Then they admitted me into the hospital, my children by then were already tired, they admitted me into Doce de Octubre, my children told the doctor... the neurologist and they ran some tests on me and then they released me.

I live with my eldest son... but he comes back late at night.

My daughter's son is now sick with bronchitis. She didn't come yesterday. But she goes almost every day for a little bit... of course! Because she has her house, she has to make lunch for her partner. Anyway, I'm not... I mean I'm here in the center. And well... when I get back from the center I call her: 'María... I'm back now'.

And a little while after that she goes and stays with me for a little while. I have a grandson, just one, that's it...

I'm very happy, yes, but oh well, I handle it more or less fine.

Well, about my childhood, yes, I remember some things. Well, I had a good time too...

In my family, I was lucky that we didn't go through any hard times, as was the case for so many other families. I've had that luck. My father was a builder of homes and well, you know, he made a good living. My mother lives with my brother in El Escorial. Just recently my mother was in Galicia, we have family there... in Galicia, and she was

they could also indicate other diseases so a doctor should always be consulted for a diagnosis: speech difficulty, complete or partial paralysis of any body part, loss of coordination, loss of bowel or bladder control, numbness or feelings of pins and needles, loss of coordination or balance, difficulty lifting one's legs that feel heavy upon walking, etc. There is no treatment to cure the disease, although there are palliative treatments to slow the disease's progression. It is recommended that patients maintain their overall health, being active, following a healthy diet and getting enough rest. Source: Glossary, www.discapnet.es.

there for a month and a half and now she says that she is going to come to my house this weekend. She's coming to visit me. And then I'll have some company. I handle it pretty well, more or less.

Yes, but you know, my children don't take me out anywhere on the weekends because they can't... Because they are working or because maybe when they have a Saturday or a Sunday free they are tired, so tired that maybe they are tired or something like that. And the only one that could take me out was my daughter, but since she has her son, well she can't either... because the boy still goes in the stroller or he walks and of course! She gets tired. And if I want to go out then I have to hire a woman by the hour for her to take me out.

And, of course, that's just another expense.

I would like it if they [she is referring to her children] were around a little more. But, of course, they have to work. And if they don't work...well no.

Social Context

Any friendships? You see now at this point... I've had friends, I had a friend, a good friend and since I've had this... If I tell you that she has stopped coming to my house! Maybe she thinks that this is... She is very apprehensive! Because before when she used to go to my house, and maybe I would say something and she was one of those that would go: 'Ay!', she would knock on wood... But my dear, I mean, about anything... any comment. Then, ever since I have this disease, she has stopped going to my house, but I mean... As if it were, as if she thought it was contagious. I have no idea. And as for me and friendships... well, I don't care. Right now I don't trust anyone. The ones that I trust the most are the friends from here [she means those at the day center]. But... friendships outside of here... Now I don't trust anybody. Nobody, nobody! And well, that's it, I would like a lot of things...

Now I'm going to go away, next month, I'm going to go to Salamanca, because there is a trip. And well, here there is another member of the center: 'ay! Angélica! You'll see how great it will be'... Because he asks me and I say to him: 'Juan Antonio, I'm a little, you know, a little tired... you know a little down and out.' 'You'll see what a good time you're going to have Angélica! When another trip comes up for us to go even farther away, going on a plane, you'll sign up too... You'll come with me!' 'Well, fine... well, okay.' I'm going with this guy, with Juan Antonio, with Maribel, from here in the center, with Javier... I mean, they're all people from the center, it was organized by the center. You know, with the social worker, with Edy and with Juan. A weekend, but it's good. It's the first time that I'm going to go away. I don't know how well I'll do.

Health

I felt like I was weak, because I would go to the kitchen to wash the dishes and many times I wouldn't have the strength to hold the pots to wash them and I would drop them. And I would say: 'why do I drop them?' And I thought it was because I was weak and I took some pills. I would take tons of vitamins on my own. That's why, when I was in the hospital, when they did some blood work... I was full of vitamins! You see, I was great! Of course, what happens is that this disease makes you tired, that is, it makes you weak. And well...that's it, I've already told you that I've had to deal with the flare-ups on my own. I thought that I was depressed... after my separation and since I didn't take anything for depression or anything of the sort ... well, I was....

The diagnosis was made in 2003. I've been in a wheelchair since 2003 and I was in Doce de Octubre for five months. I had a fabulous doctor, because of course, being

their with the neurologist, the psychiatrist and all of that, when they told me what I had, my world came crumbling down! I broke down. They would give me some talks, they would talk to me and stuff. They said to me: 'Angélica, until you become friends with the disease, you are not going to deal well with this.' Then, it took a lot for me there, with conversations with them, with the psychiatrist. And well, there came a day and I said: 'Juan, I've gotten over it'. And yes indeed, now I deal with my disease, I've moved passed it and well... I deal with it more or less just fine.

Because I broke one of my hips. Well, I didn't break it, they broke it on me here... because those guys from the ambulance, there was one who instead of ... upon taking me out, it was my stop, at the end of the route, and instead of taking me out backwards, they took me out face first, I wasn't wearing the safety belt that I wear now and I fell forward. And I broke my right hip. And then, well that was it, they took me to Doce de Octubre, and there they saw that my hip was broken. Well, let's see, that was, that must've been about six months ago. I fell on January 2nd, I said: 'I've had a great start to the year!' On the second of January was when I fell and then they brought me to the hospital and there in the emergency room they did x-rays. And I was in the emergency room and the doctors gave me the results and I was there on my back on the bed and they said to me: 'okay Angélica... here we now have the diagnosis, you have a broken hip in whatever place. Over here in this part', and he says: 'its operable'. And I say: 'Okay, I'm going to tell you something very honestly – I said to the doctor – if your mother had the same problems that I have with the multiple sclerosis, having to move around in a wheelchair, and what has happened to me happens to her, would you have them operate on your mother's hip?' He says: 'well, honestly, no'. He says: 'because with rest at home, it will heal itself.' Indeed, I was there for a week.... I think, at the Doce. After that week, I went home and the orthopedist told me that I have an appointment on the 22nd, and that with rest it would cure itself. And I rested and it cured itself. Before, I was in rehabilitation and well, that's it.

And then, of course, on the 22nd I will go to see the orthopedist at the Doce, so that he can take another x-ray. With the x-ray that the doctor takes, I'm not sure if he'll give it to me, but I'm going to ask him for it please! He is a very, very kind doctor, and since he already knows me and stuff... and I'm going to tell him please, if it's possible for him to do it for me on that very day and then I'll give it to them here and then they'll give me the rehabilitation. Whether or not they give it to me depends on the x-ray. It's to see how it is, but I mean, it's already mended.

Thank God, my head is still fine [she points to her head]. I take a lot of medicine every day, for the varicose veins, circulation, spasms, another for depression. That is why I think that my children, since they know, they trust that I am going to be fine and stuff, but... well, I'd like it if they would pay a little more attention to me, I don't know.... And since they know that I'm fine, quote unquote more or less, well... I don't know, they'll say: 'well, my mother'...

When I was single I wore glasses, and when I got married I wore glasses... and since I'm very... well, very vain with my glasses. But then as it turned out they said to me: 'Ay Angélica, you used to have such happy eyes and they are saddened by wearing glasses!' And I say: 'That's it, no more glasses!' I got rid of them. And now, of course... But it's just that with the multiple sclerosis, your sight gets worse... I'm near-sighted, I have nearsightedness and astigmatism. And I now must have even more because I can see less than a ceramic cat. I see very badly.

Perhaps it would be helpful to have the Tele-Assistance Service because since I stay home alone... And even though I always have the mobile with me and I can... for the time being, I don't know maybe within 'x' amount of months or 'x' amount of years.

When I was released from the Doce de Octubre, I left being able to throw around my arms and stuff, but now... since I've lost that rehabilitation...

Work Experience

When I was young I worked. In the X pharmacy [she names the pharmacy] on Arenal Street, it's a very famous pharmacy. I worked there for seven years, I was the executive secretary. And it was very good, I was very happy. And the people, the boss, they were all very happy with me. When I got married, I stopped working. Well, you see in my day, when girls got married, some like me for example, we took a liking to a boy because.... Well, let's just say that I obviously made the wrong choice, but above all what I was looking for was for one that was handsome and had money. I mean, I quit my job because it wasn't necessary for me to keep working. And of course, it was the worst, absolutely the biggest mistake of my life. Then came the children, of course... I have a non-contributing pension, the money covers my expenses, more or less. My children help me out a little. The house in which I live is mine, thank God. The house was already mine when I lived here with my ex. If I had something else... it would be better for me, that's for sure.

Training

I did, I did get my high school diploma and stuff. I loved to read; now sometimes I do and sometimes I don't. If it's a novel or some interesting book then I do. Then I started university and then things started to go poorly for my father in the construction business and I had to stop studying, I could no longer study the degree. I began to study stenography and typing. Which in my time was... And then, well, I got a job as an executive secretary at the X Pharmacy. I would have liked to have been an attendant, a flight attendant. Yes, I would have liked that, yes, to be able to travel. Since I can't always buy the newspaper, I watch the newscasts on television. I watch them all. I like to be well informed about the news. On TV I watch the gossip programs. Then I fall asleep. Last night there was that program, TNT, but – of course- it's on so late, at midnight, so I start to watch it but then I fall asleep before it ends. And it really annoys me. And all of those about the gossip, those that are about gossip... that Salsa Rosa and stuff. All of that, all of that. And at midday when I get back home... there are other programs on too, so, I entertain myself, I put it on... Since I don't see well ...

Inner Life

Well yes, because when this happened to me, I said: 'well, okay... come on, it's not like... I'm 59 years old, I see people here, young people here who come, who are maybe like twenty something years old and I say: 'I, for example, I got married, I've gone through all of the different stages in life, I was a girl, I've handled everything fine, I've never been sick, then I was a young girl, I had a boyfriend, then I got married, I had my children and well... I'm just about satisfied. Last year a person died who I loved very, very much, very much... And I fell apart a little! Because there are times when I'm ... I do, I'll explain it... when I'm very sensitive and I just cry. I sit and remember. I remember this person that I'm telling you about, who died, who... a friend of mine, a very special friend, indeed. Yes, he died last year in May. That's why I say that life is so unfair. Isn't that the truth? He got sick, yes. He got sick and he passed on just like that...

Current Life

Of course, I'm in a wheelchair. And well... I need help and that's why I have people that go in the mornings to get me up, to bathe me and to get me dressed so that I can go to the center. And then, there are also people that go to put me to bed because I can't do it myself. And since I live with my son and my son works, well obviously...

When they take me to my house, a person who is also from 'Cohabitaes' picks me up, from the home care help and then that same person takes me upstairs and makes me whatever I have there for dinner and then I stay there alone until nine when they come to put me into bed. Well... with the chair, I open the door for them, with the telephone buzzer when they ring up. And well, that's it. I get used to it.

At first I was very angry, very angry. Very angry because in the middle of all of this, a lot of things have happened to me, besides the separation... but oh well, it doesn't matter. That was the best thing that has happened to me. But other things, for example, people that I have loved have died... and so...

I, for example, as I say, I have to carry around Mr. Roca [she is referring to the adult diapers]. And that is what I find the most daunting, because in order for us to go now to Salamanca, I always remind Miguel: 'Miguel, you know that we have to take Mr. Roca along with us. Because I, for example... I cannot go to the bathroom like you. Then, of course, that is what most concerns me. And if I don't go to certain places, well then it is for that reason, I don't know. Even though Juan Antonio tells me not to worry. The one that told me to sign up with him for the trips. He says that very nice people are going and that I shouldn't worry about that.

They change my diaper three times a day. In the morning, at midday and at night. But I think that this is a concern held by everyone because we deal pretty well with everything else. At least I deal well with it, even though I may sometimes have my sensitive moments. I have a lot of memories, especially at night when I am alone, when the ones who put me to bed have already left and I start to think and...

Here in the center, we come in, in the morning, and we leave about four thirty or five. We do jobs, things... to memorize, we play hangman, we play Parcheesi or we play something else that I can't remember. Right now I don't have physical therapy but the others at the center do.

Vision for the Future

Well... when I'm alone in bed, they leave the television on for me, yes. Besides, I have a bed, I bought it, it's one of those like they have in hospitals... I pay for it in installments, its one of those that rises. I put my feet up and I'm very comfortable watching my television. And I fall asleep from being so comfortable. I mean, it's great. But, I mean, you know, I don't know how I will be within 'x' amount of months or 'x' amount of years. Perhaps I'll have to go to a nursing home, one of those that... I don't know, I don't know. Because here there are people, for example, that I see who were well but now they are a little worse. And I say: 'when I find myself in their situation, I will definitely go straight to the nursing home... I won't be in my house or anything...'

Let's see if my wish is granted, you see, I want, no... I don't want, but I would like to go to Holland. To Holland and to Germany. Yes, I would like that. If there is ever a trip to go there... You see the person that died was Dutch, so before, I was willing, I was wishing to go but no.... oh well. If it works out, then I will go for sure.

Comments on Angélica's Story

Physical therapy and physical exercise can be a great help for patients of MS. It is a lot easier to maintain the existing use of one's legs than to try to recuperate them when they have become incapacitated. In Angélica's case, she did not notice the disease's outbreaks and initial symptoms, and she attributed them to another type of ailment; fatigue due to a lack of vitamins and depression as a result of her marital separation process. The absence of an initial diagnosis shut the door on her in terms of the therapeutic application of preventive medicine. In 2003, once hospitalized and with a correct diagnosis, the therapy was focused on delaying the disease's progression; however, as it is an illness with an uncertain evolution, her lower limbs quickly became incapacitated, and since that time until the present she has been in a wheelchair.

Besides her inability to walk, she suffered a break in her hip six months ago, which is yet another factor that adds to her situation of vulnerability. As a result of her disease, MS, she was advised not to have surgery and to wait for the bones to stabilize themselves and mend on their own. Currently, she is waiting for her appointment with the orthopedist, as she is anxious to restart her rehabilitation sessions.

Angélica shows problems in the area of mobility; she cannot walk, stand up or carry objects. To get around from one place to another, she needs the wheelchair and the help of others. She is not capable of using any means of transportation by herself and she requires daily assistance to get into and out of the ambulance. Her difficulties in terms of mobility affect other aspects of her life, such as her own self-care and domestic life. She needs assistance to get out of bed, to go to bed, to bathe and for excretion and urination processes.

From an emotional standpoint, she is unstable, her emotions fluctuate a lot and while she occasionally manages to motivate and pull herself together and get over her disease (for example, she would like to go on a trip) at other times, she feels neglected by her family, she would like her children to pay more attention to her and be more involved in her personal care.

Her emotional responses are marked by defense mechanisms, such as those like: intellectualization, when she speaks about "how she should become a friend of the disease;" and evasion, through the use of humor, when she talk about "Mr. Roca", referring to her diapers. Such defense mechanisms are a healthy outlet and a way for her to project her integrity. Moreover, as she herself explains, the need to depend on another person for personal hygiene, excretion and urination processes, is something that affects her because it is an intrusion into her own body, which is not only related to physical vulnerability, but also to the experience of a psychological invasion.

Another key factor is the fact that Angélica spends a lot of time alone, and that she would like to go out more often; for example, on weekends. It is fundamental, in order to increase her quality of life, that these barriers of isolation and feelings of loneliness be broken. At the same time, it would also be important for her to be included in the Tele-Assistance Service.

Within the Association, Angélica has found the social support that she needs. She is very active in the different activities and desires to be reincorporated into the physical therapy

sessions. She has also found friends there and her interaction is highly positive. Taking into consideration the previously assessed indicators, her current degree of dependency is severe.

JAVIER, HIS DREAM OF WORKING

Presentation²⁰

Javier is 33 years old and lives with his family. Every day he goes to the Day Center of the ADEMM Association. His diagnosis is *Physical Disability due to Cerebral Palsy*. At the center he receives socio-medical attention and speech therapy. He shows difficulties in communicating, and uses a written transcription device. His integration at the center is very encouraging, as he is a person who is valued by the group.

Familial Context

I live with my mother, my sister and my niece. I am 33 years old and my sister is 30. I don't have a father, he died 16 years ago. My niece is two years old, and she is very small. My mother works in a school, she does a little bit of everything, the cleaning... My sister, she works in a nursing home for the aged. I get along well with my sister... sometimes we argue but that's how it is, that's normal.

I have a girlfriend, she lives in Guadalajara; we don't see each other very often. She lives and works in Guadalajara. I met her in Madrid, when I came from Albacete. Her brother has a house here [Madrid]. When she comes I go and visit her. For her, María José... it takes a lot of work for her to walk. She has problems in her legs and her hands. We always write each other letters in the mail.

Social Context

I have few friends, but oh well [he smiles]... At the center my best friend is Vicky. In June, I went on vacation to Mallorca, with my mother and one of my mother's friends. The neighbors are good people and they accept me for how I am...

Health

At birth, I was born with forceps... at ten months. I don't take any medication. Here, the speech therapist helps me to speak. Yes! With a little bit of patience. I go once a week to the center's speech therapist, a half an hour... there are a lot of us.

Work Experience

I don't work... but I would very much like to work, in something related to computers. Computing and spreadsheets, or one or the other, or both of them.

²⁰ Cerebral Palsy: is a disorder of movement or posture, which results from a non-degenerative injury to the brain before it is fully formed and developed. Besides the motor function disability, cerebral palsy is usually accompanied by other problems, even though they are not necessarily caused by it, such as: speech impairments, epilepsy, audio and visual impairments, deformities and behavioral problems and, sometimes, mental deficiencies. The risk factors may be: prenatal: all of the causes that disrupt circulation in the placenta, contagious (German measles) or metabolic diseases (diabetes) of the mother and Rh incompatibilities; Perinatal risk factors: anoxia, asphyxia, trauma during birth (forceps), changes in pressure (cesarean sections), premature birth, vitamin K deficiency; Postnatal risk factors: traumatismos (head fractures and injuries), infections (meningitis and encephalitis), vascular disorders (hemorrhages, thrombosis and embolisms), anoxia, carbon dioxide poisoning. There is no cure and the treatment should be comprehensive, taking into account both the strictly motor-related problems as well as the corresponding problems and possible complications. Treatment should begin at birth or at the time of injury, it should be initiated as soon as possible and be continuously adapted according to each stage of the child's evolution until his/her maturity. Source: Glossary, www.discapnet.es.

The pension that they give my mother... is mine. It's very little, my mother works because ... if she doesn't we wouldn't make ends meet [he smiles]. If I worked... Work is what matters to me the most.

Training

I have a primary education diploma and then I started administration and I stopped... but I've studied at the CRMF [in the province of Albacete] IT, Information technology. I went to Albacete to study IT... I went alone and then I came to Madrid. Because things didn't go that well for me in high school and I ended up there in CRMF. In that place you can live as if you were a boarder. I was there, for a year and three months in Albacete and then I came to Madrid.

I like to read books about space.

They gave this device [he is referring to the machine with a keyboard that he uses to be able to communicate even though it is broken and he is communicating by speaking] to me when I asked for it in the Social Security system, it's been broken for a while... a couple of months.

Inner Life

My mother is the most important person in my life. She is the one for me and I am the most important person for her. We both love each other very much [he gets emotional]. When I'm sad, I listen to music. Romantic songs.... Camela. It lifts my spirits... Of course! It gets me going! [he laughs].

Current Life

Breakfast, my mother washes me... she shaves me. I wait for them to come pick me up and then I come here [he refers to the center].

When I go back home, I watch television and I take care of my little niece, Alejandra.

I watch sports... soccer, on the TV.

I show my niece how to paint... to color, she does what I do a lot.

The physical therapist makes me do exercises, she opens up my left hand, and she massages my other hand.

On the weekends at home, it's my job to sweep and to dust.

I help my mother with the groceries.

Vision for the Future

I have a dream – to work! To be able to help my mother... but it will be difficult, very difficult.

It angers me... that society does not accept me because of my problem. That they don't help me.

Comments on Javier's Story

While Javier's difficulties are uniquely different to those of people suffering from Multiple Sclerosis, he shows physical limitations as a result of having suffered from Cerebral Palsy at birth. He can walk and get around with a certain degree of autonomy, he can lift and carry objects, and use means of transportation on his own. His range of mobility indicates a level of difficulty that is deemed slight: Javier can execute actions but at a slower pace. At the same time, he does not have a firm or stable enough grip in order for him to be able to use his hand, given that the paralysis has also affected his upper limbs. Nevertheless, he does

have greater agility in his right hand, and he can use both hands to get around, write and use the computer's keyboards.

Both his range of self-care and that of domestic life show the same levels of difficulty as that of his range of mobility. That is, he requires help in some aspects, such as those like bathing, dressing himself and shaving; however, there are other aspects that he can carry out satisfactorily without any assistance, when they are modified to his pace and speed of execution (for example, sweeping the floor and dusting the house).

He maintains his intellectual and cognitive functions. Over the course of the interview, despite his limitations in terms of communication, he hardly used the keyboard on the communication device and he tried to express himself verbally. Moreover, he has a good capacity for analysis and synthesis when asked open and ambiguous questions.

Javier is a tenacious and perseverant person who likes to get by on his own. The help provided, which comes from outside, is more like an assistant rather than professional care and assistance. He aspires to be more autonomous and independent. He is aware of his physical limitations, but even still, he is still always interested in helping others: his presence in the center since 2005 has been very beneficial, both for him and for the group. At the association, they describe him as "a collaborator, a motivator", he even helps his fellow members who cannot get around on their own. It is very important to highlight his social skills, since he is a person who is valued by the group thanks to his social interaction. His healthy availability is a positive sign, as it shows that he can adapt easily and that he possess inner resources that allow him to be effective in his basic and complex interactions; moreover, it demonstrates his ability to establish social, informal and formal relationships.

His participation in community, social and civic life does not present any kind of limitation. His main concern is that "society does not accept him just as he is." Javier desires to be productive and to participate actively in some type of professional work. He would like to be included in the system, not only so that he can feel useful, but also to be able to help his mother economically; she is the most important figure in his life and with whom he maintains a very strong emotional connection. Therefore, it would be highly appropriate to grant him some type of professional opportunity in a given occupational field. Such socio-occupational support would be highly beneficial to him, since – on the one hand – it would increase the family's economy, and – on the other hand – it would improve his self-esteem from a comprehensive perspective. Assessing his current activity and managing the correct means of adaptability in his professional and socio-cultural life, Javier's degree of dependency is slight.

ARTURO DOESN'T EXPECT ANYTHING OUT OF LIFE

Presentation

Arturo is 51 years old and lives alone with his 86 year old mother. He was diagnosed with MS in his forties and the evolution of his illness is currently chronic. He is in a wheelchair, with a high level of immobility throughout most of his body, as well as his voice and speech functions. He is a beneficiary of a medical service for physical therapy at the Day Center. Moreover, he and his mother are beneficiaries of the Tele-Assistance Service.

Familial Context

I am 51 years old and I live with my mother. It is just the two of us. I had a brother and in 1992 he said: 'Good bye... Good night! And he left me... that is, he died. He was older than I am, by fifteen years. We were just two brothers, no more.

Eh! Eh! Just like any other mother... eh! With her... eh! We do everything, in terms of talking, she does.... She is 86 years old and well... sometimes, it bothers me that she has to make such an effort because of me.

My father died many years ago. I'm an odd mix, Extremaduran, Galician and from Madrid. My mother is Galician, my father Extremaduran and they had me here in Madrid. That's how I explain to people where I'm from, I have an odd mix. Another thing... eh! In my form of speech... eh! I talk as if I were making fun of myself, always [he makes an effort to enunciate while he talks, he can be understood well but the sound is distorted, he speaks very slowly].

Social Context

I've never been one to go out much. Eh! On my own, before, I started to go on some trips... there was the trip to celebrate graduating from university... that was the first trip I went on. I went to Tenerife.

But now I don't go on trips with the center, it's a huge problem for me to go. Because I'd have to leave my mother here alone... and that bothers me.

Maybe I'd go... If someone would stay with her... But I don't know.

Health

The physical problems, not being able to walk, the shaking ... trying to grab something. Basically, eh! The fact that I don't do it at the speed that I would like and that I have to do it at a slower pace.

The diagnosis was in 1995... eh! I think that when I noticed something relating to this was in 1978. I was leading a rather normal life up until 1995. I felt, just at the beginning... that it was like one of my legs would get paralyzed, the right one... And since then, eh! Eh! Starting from the floor many times [silence].

My right leg felt really heavy when I tried to walk, but then it went away until 1995... It was criminal! I got really angry! I went to talk to the neurologist. I told him what was happening to me and the diagnosis that I'm afraid was... demyelinating disease... eh! Chronic, progressive and then the diagnosis of Multiple Sclerosis... it's the same name. I was 40 years old.

Now I have the Tele-Assistance Service... for both of us [he is referring to his mother too]. Every time I have a problem, well... maybe I don't call myself, but my mother calls and they send someone over.

Work Experience

At that time... when they made the diagnosis, eh! They, at Insalud, had told me to take a hike... eh! That was when I went to see the neurologist. This stupid thing... is a neurological problem. But at Insalud... You see I was working at Insalud at the time... And that's when they gave me... they told me to go to any other place.... Eh!

The job...eh! I will say it even if I don't like it. What I don't like to talk about is my profession, but I will... I'm a doctor, eh! I don't like to talk about this subject but... but if I have to do it, I will. Yes. They retired me due to a severe disability... I mean, I am a great big idiot. I often talk about myself like this but I would never talk about others like this.

Eh! I would say that they give me 150 percent of what I earned, I mean, if I earned 100,

they give me 150. My mother also has her pension.
A lot of times I... she makes the meals, she does the grocery shopping. Often she will pay for things, and the expenses...eh! Nothing to do with those... they are my responsibility.

Training

I, like a complete idiot, spent my time studying, preparing myself for my profession.
I don't like any program on television in particular, no. What I do most of the times is change the channels... to see if there is something that holds my attention but I never find anything.

Inner Life

I am always poking fun at myself, but never at others or those people that have the same problems that I do.
It could worry me ... eh! The fact that I don't have a girlfriend, but... because I've never managed to get one to stand me.... And, of course! I'm not willing to stand her.
The prettiest thing that I said to one... for example: you aren't pretty! [he stuttered a bit about what he wanted to say] You aren't pretty! Something like that!... I've spent my life doing other things. Doing what I was doing before. I've always said about you all [he is referring to women] that you are all bad and ugly. I've always said this that they were all very ugly.
Now, I no longer have this opinion... but it's late. Before, I could've liked one but I've never gone out looking for her, I've never gone out trying to get together with her.

Current Life

I get up, I come here... and we eat and I go from here back home... and I go to sleep.
Basically, nothing. Like a jerk! I watch the idiot box [he is referring to the television].
There is a person that goes for two hours in the morning to get me up out of bed and then that same person goes back in the evening when they pick me up. When they take me out of here. It bothers me that I can't do it, that I can't do it how I want it to be done.
I try to start... with this cough... and I'm usually not able to and that is what makes me upset [at this time he has had excessive coughing and the interview was interrupted briefly so that he could drink some water].

Vision for the Future

I don't expect anything anymore, nor do I wish for anything... what for?

Comments on Arturo's Story

As we have said, MS is a chronic disease that affects the central nervous system. Depending on the degree of the damage, a large number of patients have been able to maintain their health by following certain guidelines. Arturo is in a phase of the disease in which the severity of the symptoms is constantly increasing: the secondary progressive phase. After an initial period of relapsing-remitting MS, it moves to one of relapses and progression. When this happens, the patients get progressively worse, regardless of whether or not they have any new flare-ups.

As in almost all chronic and debilitating diseases, the life expectancy of the sick is shorter than that of the healthy population. This is due to complications that stem indirectly from

the disease: greater propensity for respiratory, urinary and eye infections, etc. which, in any case, are improvable with good medical attention.

Arturo's attention is quite critical; the professionals who attend to him have noted a marked deterioration. Nevertheless, Arturo periodically carries out physical therapy sessions that improve some strictly physical aspects (for instance, like treatment in support of spasticity). Moreover, he has the feeling that he is doing something for himself and that he is collaborating actively in his treatment.

With respect to his emotional state, Arturo tries to make light of his situation, and even uses pejorative terms with himself. His use of irony and jokes, are all defence and mitigating mechanisms against the critical situation in which he lives.

His greatest concern is his mother, as she is the most important person in his life and he cannot foresee the future without her. He is fearful of leaving her alone – for example, if he goes on a trip – and this situation makes him emotionally more vulnerable. His relationship with his mother is very symbolic, and the dependency ties are very strong. Moreover, his mother's advanced age is a potential risk factor and it would be necessary to implement some kind of program to give some relief or social support to his mother.

Currently, Arturo presents a situation of high vulnerability, as many of the functional areas of his body are in compromised conditions. His degree of dependency is moderate to severe in terms of carrying out many of the tasks and activities of daily life. While he has been able to study and have a career in the past; currently, his cognitive functions have been diminished, he can no longer skillfully do calculations or resolve problems.

A positive indicator was his incorporation into the center, which established a social and emotional network that he did not have previously, and it has made him change his attitude towards one that is more assertive. However, taking into account his current situation and his life story, his degree of dependency is severe to complete.

NURIA, EVERYTHING REVOLVES AROUND HER REHABILITATION

Presentation

Nuria is 31 years old; she is single and she lives with her family. Currently, she does not work and she is undergoing physical therapy rehabilitation. She is a member of the ADEMM Association, but she does not participate in the Day Center. She was diagnosed with MS in March 2005.

Familial Context

I live with my parents. I have two siblings. But what happens is that it will be a year... in November, it's going to be a year that my sister went to live with her boyfriend. I'm the oldest and now it's just my brother, my parents, my dog and me. My brother is after me, we aren't even a year apart. I get along well with my siblings... man! I'll tell you that we are siblings... there might be other brothers and sisters that are closer than we are, more united, but when it comes to my siblings, if you need help, they are going to

give it to you right away, you can count on them at any time. I can't complain, no, I have no complaints.

The person who has had the most influence on my life has been my mother. Well... I wouldn't know what to say. To me, my mother is everything, I mean... maybe if she tells me something... I don't know, if she is going to give you some advice or whatever, I'm always going to listen to her! I always think that a mother... I'm not going to say that she is always right because just like anyone else she can make a mistake, but yes, she's the one for me...

I would like to be like her, have her patience, her good nature. I don't know, it's as if I would like to be like her, because the rest... well, certainly not! In terms of patience... I wasn't in the lineup when they were giving out patience, so I didn't get any of it! And in terms of personality, well... I wouldn't say that I have a strong personality, I think that with this, you start to become softer. Perhaps, before I might give harsher responses.

With my boyfriend, things are good... it's like I say to him: 'Juan, you knew me when I was well.' You know that maybe another person would have said 'this doesn't interest me! There's the door!' No, but Juan met me when I was well... when I was ...like I say, arthritic and now with MS, I mean... no, it's good. We've been together... Damn! It's going to be ten years in January. Yes, yes, but it's good, very good.

Social Context

Friendship is important, but friends, you have few friends, because later the people with the slightest thing or the first change, well no... it's like they are not going to pay any attention to you, those that would leave you hanging. No, because thank God, I still have my friends. But... I don't know, to me... I don't know, I think and I consider my best friend to be my boyfriend.

I don't see Juan right now that often because they've changed his shift at work, and he's there in the evening, so... I might see him a little less. Not every day.

My friendships... they are the same as before but it's different. But I think that we've all changed, you know? Before, maybe when I was younger, well then I could go out and I could be out till six in the morning, seven or until they threw me out. Well now, besides the fact that life changes us all, some get married, others move away to live in Palma de Mallorca, you know? ... Everything changes. For example, I know that when it comes to going to a cocktail bar... well now I don't really have much interest. I prefer to go out to dinner calmly, and if the opportunity pops up to go out and get a drink... then you go, and if not, then it's just as good. You've had a good time, I've done it and that's it. It doesn't matter.

Health

I've been diagnosed with MS since March of last year. But since it is a difficult disease to diagnose, well then maybe, I don't know, up until then I thought that what I had was rheumatoid arthritis. So, perhaps... one thing led to the other. And... well, that's it. Progressive MS and... What am I going to tell you? I've been dealing with it. What is most affected these days are my legs, my arms, I'd say... [her voice cracks]. My arms are... well... if they are just as strong as a truck driver's, just like that! Just like a truck driver's... I'd say, my arms are... and... in the legs, especially in the right one.

Because my diagnosis was rheumatoid arthritis, especially in my right knee. And... in December with the rehabilitation from the Social Security system, the doctor saw me and told me that it wasn't normal that there was such minimal improvement since the time I started till now, and if I had only had... I mean, if I had only gone for the

arthritis. And then, well, she was asking me and she said that they had to take an x-ray of my head. Damn... and they did it. And then it was like... I might sometimes be a little scared, but I said, and if I have something and if I don't know what? And then, they did an MRI, in March... In February they did it to me and then it was when ... [her voice keeps getting lower and she doesn't finish the sentence].

In March, the suspicions were confirmed. My right knee is always, it's the most damaged... it might hurt a little when you do something, like the exercises, but only then. The thing is that sometimes they give you a hard workout and you say: 'I'm exhausted, I can't do anymore'. But then you take a little rest, you have a drink and you become yourself again.

I only take that one... it's for the MS, I take that one three times a day. Then I take one that is called Amantadine, which is for fatigue, tiredness and stuff, and I just take one with breakfast.

Work Experience

Right now I don't work. I don't work because my only occupation are, or is, rehabilitation. Rehabilitation in the mornings... On Mondays I have it in the morning and the afternoon, I mean, it's a full day. Man! You miss it, working; having your routine like you had before: getting up, getting ready, knowing that I have to be at work at nine, whatever. But on the other hand, you say: 'it's not like I'm really sick, this has happened to me... Yes, yes, but there are a lot worse things too!' Then...

I did used to work. I worked in an IT company. I was in administration. Well... at the company, during the years that I was there I did a lot of things, it's not like you do the same thing from the time you arrive until you leave, no. I started as a telemarketer, I started there, but then you evolve into areas like proposals, contracts. Then you change to support... I was in a group to support the salespeople. And then I went on to provide support in operations regarding the area of billing, the hours that the computer programmers must have spent on projects... Several things like that...

I worked for six years. In July 2004, they told me: 'Good-bye!' That is, they fired me and ... well I... it really upset me and brought me down because it was the last thing that I could've imagined happening. I mean, come on, not by a long shot. If they had told me: 'in July they are going to say to you good-bye forever!' I would've said that that was 'impossible!' But... oh well, that's what happened. It drove me into a really strong emotional depression! I don't know if that is ... what helped the disease, perhaps it went 'click!' Wake up. Anyway, I was doing rehabilitation from October to December...

Training

I was in administration but I studied advertising, which has nothing to do with it, but whatever...

It was a three-year university degree in advertising. I started studying Law, that didn't work out well and I switched to advertising and there I was happy. I finished and I started to work at that company.

Sometimes I can go on the computer, I'm doing a course in decoration. It's a distance learning course, through the Internet. While I'm at the computer, I put on music and then I sometimes move a bit as if I were dancing... a little, or I watch television... Well... it's just that the television is... In the morning, I don't usually put it on very much because I prefer to go out with my mother, you know? Even if it's just a walk to the X [she is referring to a place in Madrid], well, I like this, or I like that, or to go and have a soda or something. And if not, they put on those programs about celebrity

gossip, and you comment about whatever with whomever is next to you: 'ah... blah, blah, blah, look at what she said, leave him alone!' And if not, now with the World Cup in basketball, I've watched that too. I like to watch them, yes, I like sports.

A long time ago [she smiles] yes, I used to play sports, but that's all history now. In prehistoric times, as I call them. At first I played for... school. Later, later, there were always tennis classes. I like to play tennis. Then you start to get lazier... And well now, no. It's now pretty much forgotten. You can watch them ever so happily on the TV and even though sometimes it makes me envious, you know? I say: 'damn, I would really like to be able to do that!' Sometimes, I do think about that, about being who I used to be...

My mother had a store and I used to like everything about decorating and putting things here or taking them away, lifting, lowering, preparing the window displays... and then it would be really gratifying to see people stop in front of the store's window saying: 'how pretty!' That is what I would really like but that's no longer possible, my mother hasn't had the store for a long time now.

Inner Life

Sometimes I deal with it better, and other times a little worse. Because when you are well, it's not like you forget about the disease, but it's as if you forgot about it. Gosh. It's like, since you feel well, it's as if you can do anything, it's like the only problem you have is your right knee. But when you have a drop in energy, you say: Damn! More than anything, it makes you angry to think that it is a disease, so you say: 'there is nothing, so taking a pill, giving yourself injections, there is still nothing, as of today... that can cure it! Man! So by taking pills and giving yourself injections you can get better... Maybe, maybe...but curing yourself of it all, well no. The only thing that they tell you is rehabilitation, exercises, rehabilitation, rehabilitation... but whatever...

Well, before, maybe, I could get angry... I'm not saying that I've been Saint Teresa of Calcutta for the past year and a half, because I haven't... but it does seem that your personality starts to soften a little, or in terms of getting angry, or in terms of the bad responses that you could give... You know? Well, maybe on a bad day you can say something... And then maybe now not anymore, because you just kind of let things go instead of getting angry, because it's just not worth it to you anymore. Before, I could curse and swear... that is, bad words and you would vent by using them [she laughs].

Current Life

Man... I try to walk. The thing is that sometimes it depends on what you are going to do, if we are talking about long distances... Imagine if you go shopping! Or to a place where you park the car and from the car to where you are going there is a long distance, then that is when I do go in a wheelchair.

My father had to adapt the bathroom, so instead of having a bathtub... now it's a stand-up shower. In the bathroom I can get by on my own, and getting into the shower and all that stuff too. Sometimes, if I need help, if I am really, really tired, well then my mother, like the good mother that she is, you see we are very protective of one another, well, then perhaps my mother says: 'What do you want to wear today?' And then my mother might give it to me from my closet... you know? But if not, then I do it. Well, this morning I got my clothes myself... so you see...

I have rehabilitation every day during the week. I'm still not very familiar with everything. You know? So you say, well I go to this place, to that one, to that one and this one. Oh dear! I can't go, I have to change it because on this day I have to go to a place, whatever place...

On Mondays, in the morning and afternoon; Tuesdays and Wednesdays... then that's it...

For me, for example, coming all the way here [to the association] doesn't exactly cause me great difficulties, because my father takes me, you know? But it's just that the other one, the rehabilitation place where I go is very close to my home.

Each place has its therapies, its own way of working and... Since what they tell you is that the most important this is to get yourself moving... trying to keep your entire body moving so that the signal in your brain keeps working well or else it will go in search of other channels and all of that is, well... As long as I keep moving, I could personally care less if it's in one place or another [she is referring to the rehabilitation].

Vision for the Future

In the future I would like to... Man! Get married, work, why not? Have my house, decorate it. I don't know. I suppose that in this respect I'm just like everyone else. Having a family and all of that stuff... Having my own house, seeing myself married one day... who knows if it will be with children or having a job... Yes, that's right. Because seeing myself still having to go to rehabilitation, well, it bores me a little.

Comments on Nuria's Story

Her life story is a clear example of how, on occasion, the closest context, the family, is the emotional key for some patients who suffer from a critical disease. In her family environment, Nuria receives daily emotional support and personal care from both of her parents. At the current time, Nuria's father is unemployed and he is devoted to taking his daughter to rehabilitation every day of the week.

Nuria's life story shows how the disease has determined the family's daily life. Nuria's diagnosis is relatively recent (March 2005) and up until now the disease has evolved. Currently, Nuria can walk with the use of crutches, but when she is fatigued and feels tired, she uses the wheelchair, especially if she has to walk very long distances. Little elasticity is observed in her torso, and there is a lack of dexterity and flexibility in her arms and hands. While she says that they are strong (and her appearance is healthy), she does not have great mobility in them. Nevertheless, she can do a lot of things: dress herself, wash herself, control her bodily functions and carry out some household tasks.

The topic of personal care is a family responsibility. The emotional support leads to overprotection and Nuria's conduct in the face of this new situation is one of dependency on her parents. Such behavior is the result of a psychological readaptation, since on the one hand the disease, as a real fact, produces emotional adjustments in the family; and on the other hand, the feeling of vulnerability in Nuria is deepened as a secondary effect of the illness.

Currently, Nuria does have relative physical autonomy, which should be strengthened further and not countered in any way. Nuria was fired from her job without any type of formal explanation, even though the reason is attributed to her absences to go to rehabilitation.

II. People in situations of dependency. Life Stories.

Nuria has projects and plans for the future and, while it is difficult to foresee how this disease will progress, she possesses the inner resources to pursue her goals. The fluctuations in her emotional state are normal and an effect of the disease. Taking into consideration her life story and her self-assessment table, she has a moderate degree of dependency.

PEOPLE WITH GENETIC PHYSICAL DISABILITIES

Interviews conducted at the Spanish Association of Muscular Diseases²¹ (ASEM)

ASEM was founded in the year 1983 in Barcelona. It was created as a result of the concerns of a group of people with muscular diseases, doctors and family members to address the need to gather together and help other people who suffered from neuromuscular diseases. Little by little the association began to spread to other Spanish communities and a delegation was opened in Madrid in 1985. Currently, ASEM is present in 15 Spanish communities and has approximately 5,000 members.

The organization's name reflects the extensive variety of diseases encompassed in its area of work, as the root of these pathologies is sometimes found in the muscular system, while in other cases, it is in the nervous system and still in other cases, it is a combination of both systems (neuromuscular).

In 2003, ASEM became a Federation of Neuromuscular Diseases, and its delegations became Autonomous Associations, each having its own legal stature as federated entities of this association. ASEM is the only entity in Spain that is dedicated to the promotion of all kinds of action, activities, diffusion, awareness raising and information aimed at improving the quality of life, integration and development of people affected by neuromuscular diseases and those affecting the peripheral nervous system.

DAVID, HIS STRUGGLE AGAINST ARCHITECTURAL BARRIERS

Presentation

David is 30 years old and he lives with his mother. His disease was diagnosed when he was 18 years old. *Muscular Dystrophy* at the waist.²² He currently works and is a member of the ASEM association.

Familial Context

Well, I have a mother who is a high school teacher, a department head at a high school and a sister who is older than I am, she is 35 years old. She works in a computer company in Paris. And my father died when I was 5 months old, he was a university professor. I live with my mother. My sister lives in Paris and my mother has been here... I was living alone up until... here a year... because I lived in my mother's house, because she had been in Nice... She was under contract, in a school, in a Spanish high school abroad and I was in my mother's house but living alone. Well now... She has come back so...

I was born in Burgos, when my father died my mother took some competitive

²¹ Neuromuscular diseases are a series of chronic ailments whose most evident symptom is the loss of strength due to a progressive deterioration of the muscles or nerves that control them. They are genetically transmitted and may also sometimes be congenital, as they can emerge at the time of birth, during adolescence or in adult life.

²² Muscular dystrophy: the name for a group of disorders in which muscle size and strength gradually decrease over time, without affecting the nervous system. Source: Glossary, www.discapnet.es.

examinations to get a civil servant position and we went: my mother, my sister and I, we went to Santander, we were there for ten or eleven years, then we were in Madrid for a year. Then we moved to Morocco because my mother had a contract with a... with those high schools abroad. We were in Morocco...well, we were there for six years and then we came back to Madrid.

Well... the most important people in my life are my mother and my sister, my family. They are the most important. I do see my sister a lot. The three of us are very close.

Social Context

I used to go more often to the movies, now I don't go so often because I need to know which movie theater it is in order to know if it has any barriers, to know its accessibility... I mean, very rarely, very rarely do I go to the movies. And the last time I went, I think it was a year and a half or two years ago... I don't know.

I no longer go out like I used to, when I went out... well, Fridays and Saturdays I'd go out to the bars and stuff like that... Of course! You have to stand to do those things and I can't... Eh! But if I meet up with friends, then I do it in cafeterias, seated... or at someone's house, sitting down and stuff... Of course! This has also really limited me too... because I can no longer lead or have the social life that I used to have.

That used to worry me before... yes! But now it doesn't, now I'm used to it, I know it's what I have and that I have to live with it... and that's it. It's true that I can do less than what other people can do, but oh well... I also have a lot of friends and they are good ones.

I simply think... that I can't follow the pace of a normal group of friends or that if I try to follow them, the price is that they have to make sacrifices for me... and then I sometimes feel that... I feel that they... when a group comes, they have to go slower because I'm with them, or because they can't go to a bar because I'm with them. That's it! In terms of other things, well... it's okay, it's not like I'm missing all that much.

Above all... what for me is... the high curbs, for example... they call them architectural barriers, right? They are what most limit me in terms of everything. The barriers and then, well... with respect to the places for the handicapped... that is what I think... what would help me, what would make my day-to-day easier, it would be ... well... wherever there is a stairwell if there could be an elevator, if there could be a ramp that would make it possible for me to go up or down... of course! For me, and for others in wheelchairs, who have difficulties walking but... That is what limits me the most! There are a lot of things that I can't do... well, because there is a step this big [with his hands he shows more than 15 centimeters], and a lot of them are public buildings, it's not just a store where you are going to go shopping, a small store... No, no! For example, if you pay attention to the entrance, in a public building, a hospital and there are huge steps, next to the steps there is no ramp, no elevator, nothing... then I, every morning, I leave the car. Did you see how in the entrance there is a curve like this? [he tries to explain how it is with his hands], it's fenced off, so... I leave the car there but then I have to go all the way around to where there is a lateral ramp... where the ambulances leave the patients, and the loading and unloading zone. There is a ramp there, but the ramp only has a banister to the middle of it. So I have to leave the car, go around, and to top it all off I can't step up onto the sidewalk because the curb is too high, so I have to go along the side of the road, on the side of the road!... of course! Being very careful so that I don't get hit by a car and besides... walking... it is not easy for me to walk, which means that I could trip and have problems and have an accident. Then, I get to the ramp, sometimes it is wet because it had rained and it's very hard for me to get down from it... sometimes I have to ask for help. When I leave to go home, I

have to go... I have to get up to the banister but only to the middle of the ramp, I also have to ask for help... of course! All of this... is nonsense, and I do it every day and for me... if only there was a longer banister! Or if there was ... instead, instead of a curb, if only there was a smaller ramp in order to be able to get onto the sidewalk, then.... That would be very easy! I mean that... I really... And that doesn't cost that much money. That's not, it doesn't have to do with pensions... No, no! Society needs to be made aware and then, well... the politicians need to make everything more accessible.

Health

I started to have symptoms ever since I was a little boy and ever since I was 18 years old, when they took a biopsy and that's when they diagnosed me and then... two years ago when they did some genetic testing, they now know exactly what kind it is... Yes, more or less since I was 18 years old. Well... well, I can't run, I can't walk... it's hard for me, I fall very easily. Now I walk with a cane... There are a lot of things that I can't do! Going up stairs, getting up onto the sidewalk I can't do that either... Eh! Driving, if the car isn't automatic then I can't drive it anymore. Getting up from a chair, if I don't have a table or anything where I can support myself, I can't get up either. That's a general overview of what I can't do...

I can drive, because if I didn't get around in my car then I wouldn't be able to do much of anything, because getting onto the bus is something I can't do. There are very few buses that are accessible, I can't go on the metro either because of the stairs and I can't get down. I can, of course, go by taxi but it's very expensive. So, I have a car, an adapted car and I go everywhere by car. I have a handicapped sticker, which makes it easier to park... not much easier because people don't often respect the handicapped parking spots but oh well... it's better than nothing! Well... as of today, there is no treatment. And besides, it is far from having any because, because they know what is malfunctioning but they don't know how to cure it. So, up until there is a treatment... if there ever is... well, I suppose that there may be one in several years... but... Perhaps there will be a lot of them. But what they do know is that it's progressive... that the difficulties continue to increase and that it is likely, it's almost certain that in four or five years from now, that I will be in a wheelchair... And oh well! I mean... while I can walk... even though I do so with difficulty, it gives me a lot of freedom... But of course! A wheelchair, well it really makes you dependent. I'll have to change my car, I'll have to make changes in the house, at work. And then, in principle, in a wheelchair, in my case, I don't have an illness that also affects my breathing and my heart, which sometimes happens in other cases of muscular dystrophy... So for me, the prognosis is benign, it's likely that I'll end up in an electric wheelchair, of course! But I don't have heart problems, or problems with my breathing, which is normal... they just don't know what will happen. It's little by little... mine is progressive. Yes! It will get worse. Yes!

Work Experience

I finished my university degree in 2000. Then I took the MIR, that is, the medical examination to be a doctor in 2001 and after it I got a spot for dermatology to do my residency here in Madrid in the hospital Doce de Octubre. The dermatology residency is 4 years long, I finished it last year, that is, in 2005 and well... now I'm a dermatologist, I've been one for a year. I've been a practicing doctor for 5 or 6 years now and I've been a dermatologist for the past year. Well, I work here in this unit. I really like my job a lot, indeed I do...

I studied almost my entire degree here in Madrid, except for a year in France, I've done almost everything here. I get a discount in the IRPF because I'm... for having more

than 33 percent of a handicap, and then... well... No, no... economic aid! Just some things, for example, I don't pay the car registration tax and I don't pay the Eh? That one that you have to pay every year for having a car. It's a little money and you pay about 60 to 70 euros a year. And then, well... a small reduction in the IRPF and in regards to the rest.... No. No, I don't get anything.

Training

I used to like to play a lot of sports. I played all sorts of sports and stuff... and then, of course! As I had... as I had more symptoms and I could run less [he changes the tone in his voice], with less strength, I would increasingly read more and more and play less sports... of course!

I watch very little television, because well... I don't like it very much, except for some movie that they might put on that is good... I go on the Internet more often... that I do a lot and quite well... on the weekends and stuff. I surf the internet. I also read, I really like to read... With this disease, I've taken refuge in my studies... Yes, it's what I could do, so that's what I've done!

Inner Life

It hurts me these days, for example, to see the Pope, because of what he said they are burning posters of the Pope in Islamic countries and well, it hurts me to see this... Even though I'm not exactly Christian, it hurts me to see it. I feel as though they are attacking my world. Even though I don't agree with everything that the Pope and the Vatican say, but... I feel that they represent me, and that they are part of me. Even if you have a father that you don't agree with, he is still your father and you love him... that's how I can explain it. I would say that in reality my faith is Christianity, even though I don't practice it.

Current Life

I don't do any kind of physical therapy. There are treatments that they do, but they are a bit palliative and experimental. They are treatments that attempt to delay a little the progressive evolution, with corticoids or they give you more strength, or rather they try to make you stronger. Like derivatives of caffeine or things like that... But I don't take anything and then physical therapy is a measure that is good for those people that don't leave their homes, who can't move around that much, you know, for those people that need to keep their muscles in shape; but in my case... since I try to get out of the house and go to work and all that stuff... I don't do physical therapy. I did it for a while but it made me very tired, so I stopped doing it... Because coming from work, I then work in the afternoons at another place and I don't get home until eight or nine at night... And I'm just dead! If I had to go to do physical therapy on top of all of that.... Come on! I wouldn't be able to get myself up the next day. So for me, the physical therapy is coming here, working, moving around, I have to do this... and another thing, I have to see patients and... of course! ... that is a physical effort for me too... of course!

Right now I'm on the Board of Directors and stuff... ever since a few months or so ago [he is referring to the ASEM Association] [he laughs]. Up until then, I really didn't give much thought to any of it, I had gone to a meeting here or there and stuff... What has most helped me is seeing the people, those that have similar problems, talking about nonsense. 'That... that is really hard for me,' ... 'Me too' ... 'well ... I resolve this by using a little bar that I take...' there is something a little prehensile to it... Perhaps, it is just nonsense that you get from it, but the mere act of seeing others, listening to the stories that they tell... even if it doesn't solve anything for you... is comforting.

At the association, there is a group of parents, a group of young people who are more than adolescents and a group of adults. It is a kind of group therapy, physical therapy is also offered and you have to pay for that separately but that's okay, it's organized and it's partly subsidized by the association, and you can either receive it at home or at the association. Then we organize trips... well, for example, we are organizing a few weekends for children in hostels so that their parents can also get some rest from spending all day long taking care of their child... right? And well... we are going to a conference of the association, of the federation in Spain, which takes place in Bilbao this year... in November. We do a lot of things.

Vision for the Future

I would like to have a girlfriend, get married, have children. I once had a girlfriend, but not now.

Politics today... tends to engage in a lot of demagoguery and little, real politics.

Well, in terms of research, what seems to be the most promising is genetic therapy, fixing the gene that is bad, so that it synthesizes the protein well. That would be... the best... or in terms of stem cell research, the cells that come before any kind of tissue, which together can produce muscle, but healthy muscles... well, our hope...

That! Or injecting a healthy gene... which has been paralyzed in recent years, or through stem cell research. This is what has been popular lately and that they put... For us, it would be a huge hope... If restrictions are not placed on scientists and they are granted the freedom they need to research stem cells, it is an area that gives us much hope... and stuff. That would be in the future...right? Because right now it is far away... They shouldn't only allow these studies... but they should also encourage them. They should encourage the research! Well... this is what I feel is most absent in terms of today's politicians. That there be more research, they need to stop putting in so many obstacles and, of course... they need to provide economic help.

Another thing for those of us who have a physical, mental or sensory handicap, etc. eh! I would like for them to stop talking so much about economic aid and pensions and lower taxes... That's great! It's wonderful and it helps a lot, but there are things that are worth a lot more than money like: lowering the curbs, the curbs in Spanish cities, that would cost very little money and it would help a lot of people.

A person with a handicap can go to work, he/she may have some difficulties but he/she does well for society and besides, he/she is a happier person.

I also see that young people are not encouraged to go to work. I know people of my own age who have a disease more or less like mine and they are closed up in their homes, on the computer all day long, or watching TV... and receiving a pension and complaining because they get 300 euros and that that is very little. Of course it is little to live on! But what I see is that... these people are not being encouraged to go out and work. I see that the people that get themselves working and stuff... well, they are much happier. They can do a lot of things.

Comments on David's Story

In David's case, his inner resources, both cognitive and emotional, are highly positive in terms of confronting life in the face of critical and adverse situations. David is a fighter: he has serious physical limitations, he is aware of his disease, but he knows how to deal with it realistically, perhaps as a result of his own medical training. His greatest difficulty is found in terms of his mobility. He needs to walk carefully, using a cane, taking short and slow

steps. His muscular dystrophy is at the waist, but his disease's progression has affected his legs, making it likely that he will need to be in a wheelchair in the future.

The main symptom of the different types of dystrophies is muscular weakness: in David, his entire bone structure is visible and he has a progressive degeneration in his torso and in his upper extremities. The joint deformations limit the kind and quality of his movements and, in general, the skeletal dystrophy affects his motor development, psychomotor skills, etc. Muscular dystrophies and illnesses of this kind in many cases often go beyond the physical plane and eventually affect a person psychologically. However, David's attitude and abilities will help him to overcome his daily obstacles. He is an intelligent and intuitive person who has satisfactory social skills and makes good use of his emotional intelligence. Additionally, he also has his defences, like intellectualization.

Among the motivations that tie him to the ASEM Association is his participation in the Mutual Help Group. In it, each member is a model for the others, because he/she has the opportunity to feel and to be useful, to do something to improve his/her own situation, decreasing their feelings of helplessness in the face of the illness and thereby increasing his/her control over his/her own life.

David knows exactly how the disease is produced, as well as how science, up until today, has yet to discover the means to cure it. For this reason, he urges the promotion of research activity in Spain on "genetic therapy and stem cells", since those two lines of research can provide results for this disease.

Another aspect that worries David is the public administration's lack of initiative with respect to integrated employment. Neuromuscular diseases – as the majority of which are so disabling – significantly condition the job offers that people affected by them can choose. The majority of job banks for people with disabilities often take more into account the degree of the person's handicap than the special characteristics of these illnesses, which limit many more aspects. David rebels and gets annoyed about the lack of political sensitivity towards this group. Moreover, such support involves necessary elements so that the worker can eliminate the deficits that come from his/her disability: for example, the architectural barriers, and handling his/her job more successfully. The elimination of these obstacles, which David knows how to get around on a daily basis, would provide greater autonomy and would strengthen the personal abilities of affected people.

Currently, David presents a slight degree of dependency and his prognosis is healthy, although that does not guarantee mental stability, since his physical disability will become more chronic over time.

ASUNCIÓN, THE LACK OF SOLIDARITY IN THE DOORWAY

Presentation

<p>Asunción is 50 years old, she lives with her husband and one of her children. She was diagnosed with the disease of Muscular Dystrophy of the waist when she was 23 years old. Her symptoms were in remission for a period and she could then dedicate herself to her family. Currently, her situation has changed; she is practically inactive, even though she can still walk. She receives economic aid from LISMI.</p>

Familial Context

I have two children. The oldest, she is... she is 28 years old. Well... she is at home now but she is already independent, and then I have a boy who is 24 years old.

I grew up in Madrid, but I was born in Terraza, Barcelona. My parents emigrated from Andalusia to Terraza, and I was born there and then when I was three years old, then they came to Madrid. Yes! My parents have already gone back to Seville, and since I already kind of had a boyfriend... well, I came back to Madrid. My husband is from Ciudad Real, from a town in Ciudad Real but he has also been here in Madrid for many years, at this point... I consider myself from Madrid... with roots from Andalusia and from Madrid.

I'm the oldest, the second one is healthy, the third is sick, the fourth – who is a boy – is healthy and then the fifth one, who is a girl, is also healthy.

There are five of us and out of the five, two... My parents aren't sick... neither of them. There are other neurological diseases that are transmitted... it doesn't necessarily have to be from the father and the mother... The mother carrier, with just one, can pass it on. Each one has its own type.

Mine is a kind of muscular dystrophy at the waist due to a lack of calpain... according to what they tell me. So, there are a lot of ways to get it, for example, for muscular dystrophies at the waist there has to be... Both the fathers and mothers have to be carriers, but if they marry with other pairs that are not carriers, then there is no need for my grandchildren to have it. I don't know maybe if there is a mutation... then..

Social Context

Have you seen the building's doorway? There are eight steps, now the device has been installed... but I've spent three years fighting with the neighbors for them to let me put it in! They didn't want to put it in amongst all of us, or allow me to put it in myself.

This apartment was from Ivima but in terms of its ownership. But now it's mine, I have the deed and everything... now it's mine. I tried, we tried... we've gone to the town hall, to try to change the apartment since there were some promotions for BBV apartments, I wanted to turn this one in and for them to give me one that was adapted and they turned me away. We went to Ivima for them to change it... That didn't work either! Because they said that we already owned it... That I already had an apartment! And that I had to fix it myself... and with my neighbors... I couldn't [she is irritated].

Like I was saying... it has been three years of fighting to get them to install a type of elevator, the thing that's on the stairwell... as soon as you go through the front door, because with those eight steps, up until then I could walk up and down them... but not anymore! When you get to the landing, then there is an elevator there... but, who was going to get me up those eight steps? I mean there are eight of them on the main floor.

An elevator... I've fought for it! And in the end, I've managed to have it installed, I paid for it myself... well, I'm paying for it. I've applied for some grants, I don't know whether or not they will give them to me. We'll see.

We went to the town hall and they told us that they didn't have anything... I think that La Ocre is an organism for the rehabilitation of buildings that are not adapted or that need to be adapted. And I applied for help... If they give it to me! If they give it to me! They will give me 20 to 25 percent of what it's costing me. And that's it...

So... here in my apartment block, it's very bad. After everything that I've had to do, it's very bad. Well... there are some people here... with whom I share a friendship but... very few. It's very bad with most of them. Well... for what they did to me... for having made me go through all of that.

I am a person who doesn't like to get involved in gossip... so... well, its: Good morning! Good afternoon! And how are you? But... I mean, it's certainly not: 'Let's see if we can lend you a hand?' No! Now, when we had a problem, if they could walk over us... they have. Then... well, okay!

My social life has changed significantly... because as I was saying, I've been affected by these last three years. The truth is that I'm going to repeat that a lot ... but as of these three years, everything has changed. Before I fractured my leg and the problems with the elevator, I used to have friendships outside... I had a more active life, I would go to the parish, I gave catechism classes and now... well, I don't do any of this.

Health

Well... my first symptoms started when I was 18 years old, I would get tired when I walked, and I had always been an active person, always in a hurry... To top it all off, it happened when we went to Seville, and there are more hills there... and, of course! I noticed it more, even more. And then that's when all of the trips to the doctors started, but they didn't diagnose me exactly until I was 23 years old.

They just didn't know... it's difficult or the doctor that I was seeing didn't know where it was coming from... Where had it come from! [she raises her voice] because he didn't ever send me to see a neurologist... so, of course! I would say... My legs really hurt me! This is happening to me! 'Well... that's because you work all day long on your feet... that's what it's from'. Then, he kept putting me off, and off and then after I got married when I was here in Madrid, and I already had my daughter. My parents took me to a doctor, who was an orthopedist, in Córdoba and he saw what I might have. And then he was the one who figured it out; he told me to come here to Madrid, since I lived here, and to go to my general practitioner... he gave me a report to give to him and they sent me to Doce de Octubre. And there they finally diagnosed me.

In my case, at least the disease has had a slow evolution. I mean, I've led a normal life up until a few years ago, when I've been more limited. But it's been slow, I've been able to have a normal life; I took my children to school; I brought them home; I did the grocery shopping; I've taken care of my house... Everything! A normal life! Yes! With some limitations like I couldn't run but... that's okay! You would make up for it with other things, but ever since I broke my leg... and before that I had fallen and got a fracture, about 12 or 13 years ago... I fell into a little bit of a depression. Then, three years ago, I had the last fracture... and that depression has been the most serious yet and that's why I'm ...

I was going to physical therapy, and once they gave me, not for this disease, but out of guilt... It was because my back was hurting me a lot, because of how we walk... because we have an odd way of walking... of course! And you put a lot of pressure on your back and so my back really hurt me. They sent me to do rehabilitation ... but I was in it for 15 days, in 15 sessions, they can't do anything. Then they teach you to do some exercises, and they tell you: 'now do them!'... No! No! They tell you that 'this is a chronic disease, with no possibility of getting better'. Okay! I'm not going to get better but my quality of life is better, well... then I may be able to walk until I'm 60, no, 50 years old... A thousand things! Because if we have problems of atrophy and then to make matters worse you don't do exercise... they will atrophy on us even faster.

Work Experience

I worked in sales until I was 21 years old and then – since I got married – and at that time I was in Seville... so when I came here well I settled with the job that I had and I haven't worked again outside of the house ever since...

When my parents returned to Seville, they dragged us all with them... I'm the oldest, so we all went and after being there for three and a half years, I got married and I came back to Madrid. I started to work here in Madrid in X [she names a store] and then from there I asked for a transfer because they had the same store in Seville, another branch! And I continued working there. I started to work when I was 14 years old because when I started, ever since I was 14, because in those days you began to work at that age. Well, those 6 years or so taxed into the social security system...Lost! Because that doesn't serve any purpose! That's right! And besides the fact that you have to be actively working at the time for them to pay you anything...

I have the LISMI, that aid... which is roughly about 25,000 pesetas, it's only about 24,000 and something pesetas. In euros, I don't remember how much it is, but it's not even 25,000 pesetas, 24,000 and something, almost 25,000. And that is now frozen, the money that they started to give us, there was a little increase in the beginning and then they froze it and now there hasn't been any change ... No increase, nothing! Since 1990 or something like that... since they last gave it to me...

Training

I have a primary education diploma... yes! Then I had to work and stop studying...

I don't know what I would've chosen, but I was a good student...

In order to not get bored, I listen to music, watch TV... sometimes, or I turn it on just to have some background noise, to give me some company even if I'm not watching it, and then when I sit in bed, I read and read! I like to read.

Inner Life

I have a strong faith in my God... my faith gives me strength. It's strength! I think that had it not been for it, I would've been terrible!... Man! I've had bad times, very, very bad times! But yes... to me, God is Strength! [she says this energetically and is visibly moved].

When I'm feeling bored, sad... or like that a little, well... I put on some music [she makes a click with her tongue] to try to avoid it. And as I said... a lot of times I'll pray.

Current Life

Well, I have huge limitations now, besides the fact that in the past three years, as I've already mentioned, I've gotten significantly worse... I can't get up by myself. I walk... I go close to the walls. I get by with the walls! Yeah, but from here to the couch, you have to get me up, I mean, I'm sitting but I can't get up by myself. I don't have strength in my arms... but I can walk.

I've already [she is referring to the wheelchair] been using it, every once in a while. Because, for example, if I go out with my son, or with my daughter and I have to go walking down a very long path... well with her... it doesn't make me afraid, well... because I get tired, I fall and well then she has to lift me up and stuff... So I now try to go in the wheelchair.

On the street, when I'm with my husband, in order to not walk too much, well then I hold on to him and the crutch. With two supports. And when I was like that... a little bad in my legs... then I'll go with the walker.

I can't go out to do the grocery shopping anymore; I can't sweep under the bed or stuff like that... I can maybe sweep a little here, but I can't bend over anymore. I have to be very careful when I'm mopping the floor... because if I slip, I'll fall to the ground... well.. and then?...anyway...

I can still take a shower by myself. I had to adapt the bathroom to make it accessible, I

put in a shower or else it would've been impossible with a bathtub. I can no longer step into a bathtub, so now I have my stand-up shower that ... I have to adapt again because when you do it, well... I mean, you really don't know much, and then I found out that there are some that have a completely flat floor with no lip, no framing around it, and mine has a lip around the bottom of it and right now I can get into it but perhaps tomorrow I won't be able to ... So... I have to do even more remodeling! [she says this downheartedly].

Cooking, yes I cook... always standing. I can't do it sitting! Because I have a huge problem, if I sit then I can't get up again... so... listen to this: When my husband leaves at nine in the morning, nine thirty and there are some days that he doesn't come home to eat. He works in sales... and, of course! The hours of a salesman are terrible and then he might not come home till nine thirty at night... all day long. And if my daughter can't come to eat lunch because she works right around here in a high school, she comes but if she can't come to eat... I have to eat breakfast standing up, eat lunch standing up and be like that all day long.

It's one or the other, or I sit and don't get up anymore, or I just deal with it, being on my feet all day. Sometimes what I do, when I'm very, very tired because there are times that I can't take it anymore... I sit on the bed, since from the bed I can sometimes manage to get up... With a lot of effort! But I get up, but not from here [she is referring to the couch]. I can't get up from here anymore. I can neither get up from the chair, nor can I get up from the toilet bowl.

I've been receiving physical therapy service from the association, because our association has this service, but... of course! It's an expense. I've been, up until recently, receiving them but not anymore, I can't. Because now, with the expenses that I've gotten myself into, I can't pay... anymore! So... well, now I'll wait a while until I can. The physical therapist came to my home, the boy would come here because I can't get there, I can't get onto a bus or into a taxi, you have to get me in and you have to help me. So... I need another person, one who comes to my house. It was up until last year that I had physical therapy, but now I can't afford it.

Vision for the Future

I would like for the law to help us more, we the handicapped. Well, the truth is that I don't know much about how the law is, but they say that: 'everything is in the works'... Well, there's a project that they are going to make a lot of changes and lots of things... but the other day we had a talk and they talked a little about what the law is, and according to my understanding of it, maybe I didn't understand it right! They have created this law on behalf of aged and dependent people... Okay! I agree, but, what about us? We have to matter too! They said yes... That they are also going to broaden it to include us and stuff, but in terms of stuff about a personal assistant, it is only for people that work or study. So... what happens to those of us who cannot work or study... What do we do? We cannot leave our homes without a family member and if your family cannot... What do you do? Well... there are a lot of things like this.

Because you are young, you don't have the right to Tele-Assistance, you have to pay for it yourself... If you don't pay for it, you don't get it. Because I agree with the co-payment that says that according to what you have, you pay a certain amount... but...

Well, my daughter went to the town hall's Municipal Council, they told her: 'well, apply for it if you want to, but in your house, your mother... since you are all in the same family unit, you have salaries, you work... they aren't going to install it for your mother... that is, you can install it, but you have to pay for everything'... so?

What aid do we, young, disabled people, have? ... Well, I'm not even that young,

middle aged. You have to be 65 years old in order for them to help you... When I know people that are old, but they are in better shape than I am, and they have tele-assistance and they have a person that goes to help them in their homes. And if I want a person to come to help me, I have to pay for it and not through the town hall, but on my own... so...

Let's see. Right now in my house, there is my husband and my son who works. My son has to think about the fact that tomorrow he has to buy his own place to live and that he also needs to have money for tomorrow. My daughter works, at least now people work and they keep their salaries... he helps me, but he can't give me his entire salary! So... What's left? Just because my son lives at home, I wouldn't think of it...

The services should be channeled out of economic aid and some of the pressure on the family should also be lifted. Because if I had a person...well, I don't mean someone who is there 24 hours a day... No! But someone who came for a little while, well... to go out for a walk, well... to go out to do something at the bank or whatever needs to be done... We can't, we can't! [she starts to cry].

And then what? You stay here? And that's it!

What about those of us who aren't children... But who aren't old, or aged? I think that there is a huge gap in that regard, I don't know... We aren't studying or working, and maybe we aren't studying because we haven't been able to...

I prefer not to think about how I will be in the future. Right now what most concerns me is not being able to take care of myself on my own.

I hope that there will not be any more people with this problem. This is an issue of science and money. Everything spins around money... it's very sad, but everything runs around money... Let them work for the disabled! And let the politics just not be a bunch of words.

Comments on Asunción's Story

In Asunción's life story, we see her desperation; we see a depressed, middle-aged woman who has a progressive disability. She feels vulnerable and neglected by the system's structure, which limits her situation further. Her criticism of the Public Health system is based on facts, she speaks knowledgeably about her cause and expresses the priority needs that should be considered in the protection of the people who are part of her group.

Neuromuscular, genetic, congenital and degenerative diseases go beyond the physical plane, and end up having psychological effects both on the affected person and on his/her entire family. We witness how her family is obligated to dedicate an extremely high percent of their time towards covering the needs of one member of their family. In Asunción's case, we see how the family unit conditions its activities and daily life on taking care of and attending to her, and how she, at the same time, conditions her needs around the availability of her caregivers.

The need for home assistance, including programs of family relief and rehabilitation (physical therapy is not subsidized) are evident. For many families, overcoming architectural barriers and adapting one's home translate into important economic expenses, for which a small amount of grants are available. Finally, the management of these provisions is not coordinated and leads families to go traipsing from one entity to another (town hall, Community of Madrid, foundations, etc.). The services provided by these

II. People in situations of dependency. Life Stories.

associations do not succeed in covering all of the demands and needs of their members because, firstly, there is no coordination between social and health care systems either; and secondly, because the public funds that they receive are insufficient for the proper funding and upkeep of the services.

Asunción's physical limitations have become worse in the past three years as a result of the problems that she has had with her neighbors in terms of getting an elevator installed in her building, as well as the logical decline of her continued dependency on her family. These emotions have come to the surface recently and her sense of a lack of autonomy and vulnerability have increased considerably.

PEOPLE WITH SEVERE MENTAL ILLNESSES

From a health care perspective, the study, treatment and understanding today of mental health still represents an open field. Unlike physical ailments that are clearly noticeable, objectified and tangible, mental problems are a source of disagreement, conflict and malaise in the scientific community. Discrepancies in psychological diagnoses have compromised the work done in the field of mental health, which has forced the field of psychiatry to constantly defend and redefine itself.

The practice of mental health means bringing together efforts among professionals, psychologists and psychiatrists in order to work jointly towards the comprehensive understanding of the human being. A psychiatrist is a medical doctor, he/she has a physical perspective of the problem and is authorized to apply chemical treatment. The psychologist is not a doctor, but from his/her clinical perspective he/she can understand the physical implications of the nervous system and sensory mechanisms, as well as a person's emotional baggage and existential aspects. Therefore, both interdisciplinary contributions should complement each other and work for and with the patient. Each professional, from an ethical and scientific standpoint, should contribute to improve the affected individual's quality of life.

The massive deinstitutionalization of mentally ill people that took place in Spain and in many other countries during the 1970s and 1980s, marked the closure of institutions that were called "insane asylums," which forewarned against the *iatrogeny* of hospitalization, excessive alienation and the accreditation of a new illness: institutionalization. However, the current situation in Spain involves a persistent and chronic deficit in alternative resources, aside from hospitalization, in crisis situations. This situation turns psychiatric wards of general hospitals into the only means of psychiatric medical attention, which then in turn absorb all of the problems associated with mental health. The result of this deficit in alternative services is the saturation of these wards, which occasionally reproduce the "insane asylum" model.

The lack of alternative services for mental health attention fundamentally speaks of the almost complete absence of a network that articulates the progress made in treatment and care, that is, clinical, epidemiological and experimental advances. Without a network, band-aid solutions are administered and planning is very difficult. The network can be defined as a group of services, resources, mechanisms and social goods that can be adapted to the comprehensive needs of patients; this network should have centralized management and public financing.²³

In the coming decades, it will be necessary to cover a wide array of problems, new and emerging pathologies of the population and of demographic, social and lifestyle factors that will have an effect on the appearance of psychopathology.

In regards to the autonomy of people who suffer from mental illness, while many conditions are disabling, it is possible – with the right support networks and resources – for them to hold jobs and become integrated into society in a normal manner. However, the

²³ The AFEME and FEAFES family associations criticize the distorted image that is given to the mentally ill and call for more equitable funding in the public health care system's allocation of resources to mental health care services. They also call for coordination and legislative support between judges and the administrations.

unemployment rates of this group of people are very high because of a series of factors. Along with the problems of job insertion, the current system of non-contributing pensions – minimum subsistence – are not guaranteed for the mentally ill. Some type of basic income is necessary so that these people can secure part-time jobs, or pursue a degree, training courses or volunteer activities, etc. without having to endure the pressure to which they are so often subjected. As such, they would be able to consider entering the working world in a healthier way.

The issues related to informed medical treatment is another important topic. The Confederation of Mentally Ill People (FEAFES) and the Spanish Committee of Representatives of People with Disabilities (CERMI) call for judges to authorize the administering of involuntary treatment to mentally ill people, when it becomes necessary. Many families see incapacitation as the only path or option that they can resort to in order to get their sick family member to undergo treatment; however, in practice, there are no direct measures in effect to apply this measure without the patient's consent.

Families and those suffering from mental illness have the right to receive information about supporting and treating a mentally ill person, as well as seeking out emotional and psychosocial support. The family, the mentally ill person and the professionals should be able to cooperate on equal terms. Family associations should be represented in the organisms for counseling, policy and support of the Mental Health sector at all levels. Moreover, mental health should be adapted and developed to provide individualized attention, with modern facilities and intermediary mechanisms between traditional psychiatry and comprehensive home care.

In Spain, it is estimated that roughly 300,000 people suffer from a form of some chronic mental condition. The quality of life of this group should take into account the following factors: a) subjective measures, besides objective ones; b) factors of one's well-being, satisfaction, functional state and contextual factors; c) assessment of various areas and the needs of psychiatric patients; d) inclusion of the psychopathological symptoms in the ranges of quality of life; and e) the relationship between time and quality of life.

Interviews conducted at Doctor Lafora Hospital of Madrid

The interviews were conducted in the hospital's Long-Term Hospitalization Service; this service has the following characteristics. It covers the needs of long-term hospitalization of Area 3 (the districts of Alcalá de Henares and Torrejón de Ardoz), Area 4 (the districts of Ciudad Lineal, Hortaleza, San Blas and Barajas) and Area 5 (the districts of Alcobendas, Colmenar Viejo, Tetuan and Fuencarral). The service has 192 beds that are distributed into four units: Unit 1 of Long-Term Psychiatric Care (UCPP1), with 50 beds; Unit 2 of Long-Term Psychiatric Care (UCPP2), with 32 beds; Unit 3 of Long-Term Psychiatric Care – Rehabilitation (UCPP3), with 60 beds; Unit 5 of Long-Term Psychiatric Care – Psycho-Geriatrics (UCPP5), with 50 beds. The admission of patients is determined by decisions made by the teams that attend the patients on out-patient bases in the Health Centers of the corresponding district. The professionals at the hospital, therefore, do not decide which patient gets admitted. Hospital admissions into the service are always negotiated between the hospital professionals and the health care centers that will take responsibility for the patients after his/her admission. Patients, during their stay in the service, are attended to in the context of an Individualized Program of Rehabilitation. In many cases, what keeps a

patient admitted into the service is not his/her clinical symptomatology, but his/her instrumental deficits and the absence of external support in regards to those who have a lower capacity of autonomy. While the service's fundamental mission is to try to rehabilitate the patient as much as possible and to get them reinserted into their environment, occasionally, perhaps due to a lack of internal structures, it acts as a means of containment (social alarm) and also of institutionalization, which are aspects that should not be dealt with in a hospital setting.

SARA PLAYS WITH HER FOOD

Presentation

Sara is from Madrid, she is 33 years old and she has lived in the long-term care unit of the hospital for five years. Her hospitalization in other health care centers began nine years ago. Her diagnosis is *Anorexia with a Personality Disorder*.²⁴ She currently has a boyfriend in the hospital and sometimes on weekends she visits her family on weekend leaves.

Familial Context

Well, we were seven brothers and sisters, now there are six of us... one died at 18 years old, when I was just a year old. My father died of lung cancer, I have a brother who is paraplegic who they have operated on twice for brain tumors and my mother is at home and I... with my mother... she doesn't understand me, she thinks that I'm a little girl and if I go out she has to go with me... and 'Where am I going... What are you doing? And then, I have three sisters, one is a widow, she doesn't want to work because she says that she's 50 years old and she says that she doesn't want to work. She goes to my house and on Sundays and the weekends [while talking she imitates her sister] while puffing her cigarette... and I'm cleaning, helping my mother and everything. And then there is my sister Inma and my sister Mari. And my brother Satur, the paraplegic and my brother the waiter.

They all live in X [she names a town in Madrid]... and besides my brother, the paraplegic, his wife is an alcoholic. She was here [she is referring to the hospital] but she started drinking again... and they are going to separate... but my brother says that they aren't... Once, she hit my brother. She goes out... she leaves him alone. I worry about what is going to happen to my brother, because that woman is an alcoholic, she goes out and leaves him alone.

I have seven nieces and nephews and three grand nephews and one on the way. My father died about eight or nine years ago...

My mother is the most important person in my life, her and my boyfriend. My boyfriend is because he has been helping me a lot, because I have problems when I lose weight... during the first week, you can't leave, you can go out around here, but you can't leave the hospital. And this guy, last week when I was in pajamas... I don't know if it was last week or the one before [she tries to remember] ... Well, he came for an hour in the morning and an hour in the afternoon to be with me and he brought me coffee and he lifted my spirits...

I'm not going to go back to my house... because my mother and I get on each other's nerves. My mother is 76 years old, she is a very old woman... and [a short silence] and she doesn't understand me. Go back to my house... no... because when I go back to

²⁴ Definition of anorexia: abnormal loss of appetite. It is a situation in which, while presenting physiological conditions to get hungry, the act of eating does not take place. Source: Glossary, www.discap.net.

my house all she does is scold me for no reason. And well... I hurt myself, instead of hurting her... well, I hurt myself... Throwing up ... or doing something else!...

Social Context

Friends... they're there for the good times but not for the bad ones. I don't have friends! For a friend... you have yourself, because people ask for a lot around here, and they go after their own interests and that's it. I had a best friend, I remember that summer... I think it was summer... she was going to help me... ah no! The other summer, she was going to help me... I haven't heard from her, and she was my best friend ever since I was six years old... and I haven't seen her. Because I also drank, and I locked myself up in my house for a month because I was afraid to go outside... because I could see how the people looked at me because I was fat and there are times when that happens to me... and I'm afraid to go outside because the people look at me because I'm fat.

I had a friend who committed suicide... I don't know! ... That's what I tell myself. And I feel guilty because she never, never... she never told me that she was going to kill herself... nothing! Because I do... when that happens to me, I say it. She told me that she had to do some things, but if I had known it... then I would've told her to come to my house with me and I feel guilty for not being able to help her because she could've been here with me or in her house. She died last year.

Health

Here... I've been for a year, but I was in other hospitals longer. I was in the one in Alcalá for a long, long time... I would go and leave, go and leave.

Then my sister... said to my brother-in-law: 'That I was going to die!' She came from her husband's town to take me to the doctor for the first time... 'you're going or I'm going to call the police! Because I won't allow my sister to die.' And they took me... and then I was in the nutrition place at Alcalá, but then in a week I left at 42 kg and the week after they brought me back and I was 34 kg. Then I tried to kill myself many times; I was also in Alcalá's psychiatric ward; I swallowed two pieces of glass, and everything... and I also drank a big bottle of perfume to kill myself... and once I took five boxes of pills, I took them at ten in the morning and my mother didn't realize it until eleven at night... I almost kicked the bucket that time!

Because... I had been in a relationship with a boy for ten years, and then I called him on the phone because he didn't call me and he told me to go find another boy or a friend... and two days later he got married. He was cheating on me while we were together... he was being unfaithful to me...

I hadn't realized it. When I met him... because he had started to tell me that I was ugly, that I was fat... because I used to weigh more, I weighed 55, 65 kg. Now I weigh 43... and he started to say that if he left me then nobody was going to want me, and I didn't eat anything, and every time I threw up he would make me eat my own vomit. My own vomit that I had thrown up, he did this to my head [she lowers her head as if to indicate that he hit her]. And he would tell his mother, and his mother said: 'Well done, son!' When I was fat...

He betrayed me, he would make you feel really badly. Hmmm, first I was in the Ramón y Cajal, when I weighed 47 kg, more than I do now... since now I weigh 43... that was the beginning, when I got anorexia; I don't think that I have anorexia now... I have bulimia, because I'm fat. And well it was there, that I started to realize, he would come to see me, with a friend of his sister's and... in front of my face he would touch her butt and they would take pictures of themselves. And on my birthday... well, he was in the

military, but he chose to go out and party with his friends from the military... and he didn't come to my birthday, and they had given me a leave that day to go home. I smoke a pack of cigarettes in the morning and another one in the afternoon. Yes! But I used to smoke even more, I used to smoke packs of 25 of Fortuna, I would smoke 5 packs a day. Even more when I was in the hospital in Alcalá in the psychiatric ward, I could smoke all that I wanted to, and that's all I did... smoke and smoke...

Work Experience

Yes, I've worked, I worked for ten years in an international candy factory in Torrejón, it was next to my house. About five minutes away from my house... I would go at five thirty because at six I started work, until two thirty. I didn't eat the candies because they would penalize you. I liked the work a lot, but even more because I got even more work done than the rest of them...

I stopped working because I stopped eating, throwing up... and I weighed 34 kg.

Now, they give me a pension of about 60,000 pesetas and I used to earn about 130,000 at the factory, plus another 30,000 from some Saturdays when I would go from eight in the morning till one to clean the factory...

After finishing my primary education, I went to my sister's house because her mother-in-law was there and I was taking care of her mother-in-law and my nephew because my sister said: 'instead of getting a girl that I don't know, I may as well get you since you're my sister and I trust you.' Instead of being worried about someone taking something of hers! And my sister paid me 30,000 pesetas, she fed me, I slept there in her house... And I would say... I didn't want to accept the 30,000 pesetas because I would go to buy something that I said was pretty and my sister would get it for me.

Training

I have my primary education diploma...

But what I most like is to listen to music... I love it! Listening to music and dancing... I love it! I listen to music on the radio because my mother has bought CDs for me many, many times and I've broken all of them [she smiles]. I don't watch TV... because they only put on unfortunate things and ... to see misfortune, well we have enough of those and we don't need to see more of them...

On some weekends I go home, I go by myself or with a boy that I'm dating, who is here... He is a really nice guy, very considerate, very affectionate, not like my boyfriend, who would buy me gold things and then thought that that was going to make me the happiest woman in the world, but then it was my birthday and he wasn't there. What did I care if he spent 60,000 pesetas on some piece of gold... if he wasn't even there on my birthday. I don't appreciate that. What I appreciate is to be loved, and supported. This guy... well, he supports me... and when I'm not doing well, he helps me and he gives me advice and when he's not doing well... I help him. That's what couples are all about... the good and the bad... we've been together a year now.

Over the summer we went on vacation, we got depressed... well, I got depressed! I wanted to slit my wrists, the aids weren't there because they had gone out for drinks. They left me there in the hostel... and Miguel, the boy [she is referring to her boyfriend] called them and they told him: 'we're on our way,' Yeah!... We're on our way and it took them two hours. The police came and the ambulance... they told me that we were going to go to the hospital for a shot... to talk to the psychiatrist. And I heard them say: no, no! Let them admit both of them... because what if something happens and we are going to go to sleep and this and that...' We were at a place at the beach [she tries to remember], at a camp hostel with the aids and they took us to a psychiatric ward there...

They deceived us, they told us that we should go with the police, and they didn't go with us or anything. They told us, tomorrow you are going, and I had a very important wedding to go to on Friday, my nephew was getting married. In the end, I was able to go because the ambulance came on Friday. Those people wiped their hands of us... they left us there, it was really terrible.

Yes! I had cut my wrists, but I hardly cut anything... They admitted both of us, and I was having a really hard time, and I said to the psychologist: 'look, I'm having nightmares.'

Current Life

Well, when I get up, the first thing that I do is open the window so... in order to air out the room and the bed... Then I make the bed, then I get the clothes that I'm going to put on and I shower. After taking a shower, they give me a cigarette, we smoke a cigarette and then I have breakfast. After breakfast, I go down to the cafeteria and have a black coffee. I really like coffee... black coffee! And then at ten after eleven we go to therapy, we do things... like we might read an article in the newspaper and then summarize it on a sheet of paper. And we also have relaxation, we watch movies, we play games. We are going to make a collage ... cutting and pasting pieces of paper...

After therapy, you go upstairs, eat and after lunch, if you want you can take a rest... A lot of times I do needlework, which really relaxes me, it relaxes me! But there are times when I'm so tired that I take a nap... This week its my turn to work in the dining room because every week two people work in the dining room. So, at about a quarter to four, I set up the dining room for snack time and at four we have a snack; we set out cups, glasses, first the Nescafe, sugar... cookies. And then when we clean up we take everything away on the cart.

Then I put out the dinner and set up the plates, glasses, and then at eight they open up our rooms... when we finish dinner, we can lie down until twenty to ten... and they close the door, and then at ten thirty, they give us our pills and they give us... depending on the shift, one or two cigarettes and we have to turn over our tobacco and the lighter. And then, well, we go to bed.

Inner Life

Today... I have my moments, because since I also have a personality disorder... well, there are times when I'm very up and then when I'm very down...

When I'm on a high, I'm very happy, and I do a lot of things... like tidying up, cleaning, dancing, talking a lot... and when I'm down... well, I get really nervous, I yell, I want to be alone in my room and I cry, I think about killing myself. There have been other times that I've tried to do it but I've never died... but then I say: 'why am I going to try to do it? What for? So that I'm worse than I am... You see there have been cases like these in which people have tried to kill themselves and they ended up worse than they were before...

I either eat a lot or I eat a little, it depends... if I eat a lot then I throw it up. From throwing up, all of my teeth fell out, these are all fake, they aren't mine... Since I had money saved from when I was working, I got my mouth done... and I got glasses too.

Vision for the Future

I would like to be a normal and everyday person and to be able to do the things that you do or that a normal person does...

Comments on Sara's Story

Sara presents a diagnosis of Anorexia with a Personality Disorder, with suicidal behavior. Eating disorders are serious illnesses that affect a growing number of patients, especially young women. In our society, the desire to lose weight has turned into a true obsession and only on a few other occasions has the number been so high of women who feel terrible because of their bodies and, especially, because of their "excess weight", albeit real or imaginary.

We see a distortion in Sara's perception of her physical state, since she is in a situation of undernourishment. Throughout her discourse, she mentions on repeated occasions of her food binges, which lead her to make herself vomit after having eaten too much, that is, so-called bulimic behavior. Anorexia and bulimia are not physical illnesses on their own, although their effects and consequence certainly are. These nutritional disorders constitute a very complex mental illness that involves perceptive, emotional, relational and social elements.

As already mentioned, there is suicidal behavior in her psychopathological profile. Suicide, or intentionally self-inflicted death, is the exit to a crisis or to problems that bring suffering to a person, because of: desperation, unsatisfied needs, hopelessness, loneliness, lack of alternatives, the need to get away or escape from something, frustration, etc. The person does not seek to harm him/herself, rather he/she is looking to put an end to his/her difficulties, looking for a way out because he/she cannot stand what he/she is living through or he/she cannot find any other alternative. In Sara's discourse, she makes several references to her suicide attempts and to her recidivism. Such attempts should not be underestimated, even if the person says that she was only looking to get someone's attention (it is not true that a person who says they are going to kill themselves, will never do it, since eight out of ten people that commit suicide let somebody know that they are going to do it before they actually do it). In sum, the factors that trigger suicide attempts can be attributed to many reasons related to the lives of each subject; however, they are generally the result of an identity crisis and vulnerability in the face of chaotic, aggressive and negligent settings, where there are troubled interpersonal relationships and family environments.

In order to understand Sara's vulnerability, her many years of hospitalization in various centers and her residency at a long-term care facility must be assessed. She has spent more than nine years in hospitals, which makes her situation of dependency worse, even though the best thing for her treatment is preventing and stopping her suicide attempts, which can be done there. The description of her social relationships as having deteriorated appears to indicate a lack of support from her family, which leads to an increased dependency on the hospital and lower personal autonomy. Her hospital records lead us to infer that she initially received outpatient attention and that as the years went on her hospital stays became longer and longer. She is currently contained in her treatment, but it is not known whether the service could offer her any alternatives at times of crisis. At the same time, it is difficult, and perhaps even impossible, that – regardless of the therapeutic wishes of the professional – the structure and capacity of this service can create intermediary measures in terms of a search for opportunities and increased personal autonomy. Taking into account all of Sara's background and history, her current situation of dependency is severe to complete.

ERNESTO: “I WAS GOOD AT IT, AND THAT’S SOMETHING”

Presentation

Ernesto is 32 years old and he has lived in the long-term care unit of the hospital for the past three and a half years. He has been diagnosed with “*Drug addiction and a personality disorder.*”²⁵ He has a lot of difficulty in communicating, that is, using coherent language.

Familial Context

I was born in Burgos, in Miranda de Ebro. My father died, my father died of cancer. My mother, well... my mother, I don't know how to say it, it's like she doesn't know that I've been here so long... what I would really like, and... I would like to get out of here at some point and be a civilized, normal person, and you know... help others, be the one that works in... I have my plaque in the apartment where I used to live...

I have a sister who is married and she has a son who is two years old... my sister is younger than I am. My mother comes to see me once a week, my mom, my aunts and my cousins...

My mother can't have me. She can't have me, she can't!

My mother lives in Parla, she lives with her boyfriend. When my father died, my mother got a boyfriend... she has a boyfriend, they live together. My mother comes... she comes... they won't find out about this, will they? [he is afraid that someone will listen to the recording that we are making of the interview]. My mother forbade me from using tobacco, 'it's bad for you!' But the tobacco puts me at ease.

Now I'm Ernesto, a sick man who unfortunately fell into drugs and regrets it. I'm so sorry that when my father died... well, they called me, my sister said to me: 'Did you know that Dad died?' I started, I started... I mean, I messed up, I really messed up.

Let's see, it must've been when I was 24 or 25 years old, more or less that's when my father died...

With my sister, well, with my sister... My sister is a great person, my sister is wonderful, she is a woman, a lady... Mother to her son, so is my nephew... My sister is 40 years old, and my nephew is six years old [the statements contradict themselves].

Social Context

No, I don't have any friends! But my best friend is ... Prudencia, she is my best friend. I don't want to lose her because I love her, I'm in love with her, I don't mind saying it... Because I am! I am! And the day that she leaves... I don't know what I'll do, but I'll do something... She is here, I don't know what I would do if that woman left here.

Antonio is a friend, he is a friend that talks to me and he helps me, he encourages me and stuff... The Red Cross... you all have a lot of courage, a lot of courage... going to Africa or going to other places to help...

Politicians... I don't trust them, well... I don't trust, I don't trust them because right when it happened, when the trains happened... well, Zapatero, before becoming president, I saw how he did it, he got flowers and just left them there... I think that he was being cunning so that people would say: 'wow, look at what Zapatero did, he brought some flowers, poor guy...' as if he were saying, 'maybe now they'll vote for

²⁵ Drugs: all chemical substances that are capable of affecting physiological or mental functions of human beings. They can create some form of habit or dependency in those that consume them. Glossary, www.discapnet.es.

me...,' they voted for him and he became president and Rajoy... Zapatero is more serious, more serious than Rajoy. Rajoy is more...
I haven't had any serious relationships, I've had a lot of girlfriends... before and a little while ago... it's been a year since I last made love, I don't have a girlfriend or anything...

Health

I've been here for three years or so, almost three and a half years, more or less.
I have to wait a little, I'm still taking methadone, because I was addicted to drugs, I'm an ex-drug addict ever since six years ago, now that stuff makes me sick, it makes me sick. It makes me sick to talk about drugs, truthfully it makes me sick to talk about drugs. Ah... it makes me sick because I stopped using them ten years ago and I feel like the happiest man in the world. So... I mean I have... the happiest man in the world! And now, I ... I trust the Red Cross very much, I trust you guys a lot, I have a lot of trust... eh, that, that you all help, you go... you go all the way to.... To help others, you help! And that's, that is... how do I say this... it's a beautiful thing, helping, helping, helping!
You help others, for example in the neighborhoods like, I don't know, the people with AIDS. I can now go with the antibodies... No one is listening to this, right? [he is asking about the recording of the interview], with the virus but it hasn't developed... you understand? It hasn't developed... and well...
It's been ten years miss... since I last tried or took drugs. Ten years, ten years... I assure you! I haven't tried drugs in ten years, that I can....
Well... I'm not exactly sure miss, I can't really say, I can't say, because, because ... they brought me here, the ones from Leganés... The ones from Leganés, I mean from the hospital in Leganés... they brought me here and... well, I mean... the first year was fine I could stand it, I could stand the second year, and I stood the third year, since I would ... rarely, rarely... get a leave for a week... or else on that rare occasion that I would go out... it was... a shared place, like, it was like a residence. Well then, honestly, I don't see myself like those other people that went [he is referring to the patients in the hospital]. I haven't been like them. There have even been people that have said to me: 'well, your father... why isn't he here?' Well... I don't know. It's because my problem isn't a mental one, it's the other thing that makes me turn to... to...
I am uncomfortable, here I am uncomfortable. A little uncomfortable, a little uncomfortable because well, you see, I don't know... I ... I would really be happy outside of here, I would be happy, I would be happy, happy. The doctor... I don't go to see her right now... she tells me that some year I can leave, some year, some year... but that year never comes... and you eventually start to get bitter, I get bitter. I mean, the morning comes and you look out the window and I say: 'one more day, one more day, it's another day that I'm alive, another day that I'm alive.' Because my problems are the antibodies, the virus hasn't developed, I know I am going to die.
In Leganés, I was in the hospital, but there I would go to workshops... I mean, there I learned how to cook, that was in ninety-something.

Work Experience

I've been a locksmith, a plumber, a waiter, a lathe operator. I've worked in a lot of things.
I've worked in Civil Protection, for example, yes ... ironic... so that there weren't any fights with the musicians or with the people that were going to sing at parties... working... things more or less like that.

When I was 16 or 17, I met a guy at a club, a friend, he worked... [what he says cannot be understood], he was 25 years old, well... he offered me to try it... Heroin! He was the one who made me do it, he said: 'you can't be a cop, you can't be a local officer, working as a police officer and being with me doing this! So just leave it!' But I was dumb, because my profession was civil protection, it is my profession, it's what I love... I would like to... I don't know, ... leave here and go back to civil protection... go back to being... even if I had to make do with the pay... volunteer... Go back to doing civil protection...

I had my uniform and all that stuff. And now... in my company, spend some time here and then leave... because I consider myself an active person... but these are decisions made by the doctor... What I want, what my wish is, is for you all to be as good as the Red Cross, because you are professionals, you are and I have been too...

Did you know that I worked in television? Well... I've worked in television... as an extra, in Ana García Lozano's program... the niece of... Well, I would go there, I did fourteen programs, they would give me a little part with a script that I would learn. They would say to me: 'Look, you have to ask that person or someone else' and like that until... Ana, the host, would come and she put the microphone to me and I would speak. I would say... I would say, well... So I got to do 14 programs, and they paid me a thousand pesetas per program, I mean, for the two or three hours that we had to be there... they paid us a measly amount, but oh well... At that time, I was famous... I'm not, I've changed a lot. I'm no longer that Ernesto, I'm not the guy that was on Telecinco, or the one that was on Telemadrid...

Now, the economic aid is very small... I don't know if it's 47 or 48 a month... very little.

Training

I studied up until the sixth year of general education.

I like music, we all listen to Discmans, well, I like heavy metal music... You'll have noticed that from my pony tail, my earring... I'm a bit of a heavy metal guy. I like Iron Maiden, Skorpio, Sangre Azul... Barón Rojo. I like a lot of types of heavy metal music. Rumbas, I like rumbas. The Charlies, the Chichos...

Come on! Dancing! I love it! I love to dance, I love it...

Inner Life

Because I know that I'm going to die... I'm going to die, I'm going to die... I can tell you that. I'm going to die... because of the antibodies, I'm going to die... If I die, well, look... it doesn't matter...

In my life... [a long silence]... in my life... I can't say it [he cries], I can't say it... I can't say it, I can't say it, I can't say it, I can't say it... I'm sorry, I'm sorry... I'm sorry miss.

I look at myself in the mirror in the morning and I say: 'okay, I say... I'm ugly.' I look at myself a little and I say: 'perhaps I might be good looking, perhaps I am ugly...' Indecision... I can't figure it out... whether I'm good looking or not... What do you think?...

Current Life

Well... well... for example, first I wake up... After a few minutes go by, I go to the shower, I take a shower or, in my case, they help to shower me and then I get myself dressed, I have breakfast and I go down to therapy... and then in the afternoon I'm free...

I can leave now... Doctor X [he says the name of the doctor] has given me leave passes for Wednesday and Friday afternoons and the weekends, I really love the doctor. I love him very much because he has been helping me ever since last year, since October of last year he has been helping me... eh, and he encourages me, he encourages me! Gosh... I have a doctor who loves me, I'm going to fight, I'm going to fight. I have an aunt who'll love me when I leave... well then I'm going to fight, I'm going to fight. Because life is about fighting, not about feeling sorry for yourself, not about feeling sorry for yourself... You have to look at life with happiness and live it happily. This is my case, but the thing is... [a long silence], I'm seeing how the time of my death is drawing nearer... because I know that I'm going to die...
Sometimes, sometimes they come to get me... to get me up... I don't prefer to keep sleeping, but it's the way that they... their way of acting! I don't like the way they do it. Come on... come on... come on... get into the shower... Come on... over there! This morning they came in and got me up at ten after eight...

Vision for the Future

I would like to go back to working in civil protection here in Madrid, because I'm good at it, I was good at it. If I was good at it, that's something... they had given me the diploma and the license for fires and first aid. Miss, that diploma that they gave me has disappeared...
In the office... I was well dressed, in uniform... maybe they might've told me a few days before a service... and I would do it. Well, like I was, I was, I was in... with X's [he names a politician] bodyguard. I was also at Frenesí concerts, a rock group, I was at the Tour of Spain, I was keeping watch and well.... Watching to make sure that nobody got through and when someone tried to go by in a car I would honk at them.... Doing my job, doing what I had to do... even if they don't pay me...
I go out on Saturdays, I go out on Sundays... but.. but.. I want to go to a residence facility, I want to go forever, I want to go forever. Because if my mother doesn't want me, who is going to want me?...

Comments on Ernesto's Story

Ernesto's life story is hard to follow. On the one hand, when asked questions that emotionally challenge him, he is evasive and quickly changes the topic; and on the other hand, he is extremely theatrical in his feelings and emotions. While his psychopathological profile cannot be confirmed, Ernesto admits to having addictive conducts and, specifically, a dependency on drugs, i.e. a bio-psycho-social illness that involves many factors.

Some of the most typical symptoms of addiction are the damage or progressive deterioration of one's quality of life, due to the negative effects of practicing an addictive conduct, and the denial or loss of control or self-deception, which is presented by a difficulty in perceiving the relationship between the addictive conduct and one's own personal deterioration. Usually in these cases, it is the use of drugs – despite the damage – that is manifested in the continued consumption of psychoactive substances, in spite of the consequences on the person and his/her family.

In Ernesto's case, the added factor of having contracted AIDS as a consequence of dangerous practices in drug use makes the situation worse; currently, though, he is a carrier

and has not yet developed the disease. This piece of information is a negative factor for him in terms of thinking about his future.

Ernesto currently receives hospital and residential care; that is, on the one hand he receives aid in the form of detoxification with methadone, and on the other hand, within the therapeutic community he lives together with other people in recovery. The latter aspect does not effectively contribute to his recovery... given that in long-term hospitalizations, the population of the mentally ill take in a wide array of pathological profiles, and addictions are just one among many others, which usually leads to a delay in the progress made by patients. That is not to say that Ernesto does not suffer from a personality disorder, but rather that the residential hospital structure does not provide healthy conditions for an intervention in regards to his recovery. Ernesto states that he “does not want to be there”, highlighting that there is a part of him that feels he does not belong in that context. The lack networks and alternative services contribute towards increasing his levels of dependency, considering that added to his difficulties of personal autonomy, is an overwhelming health reality.

During his story, theatrical traits of his personality emerged, especially seductive behavior, which is demonstrative of his attempts to always try to get someone’s attention. His emotional reactions were very varied, ranging from positive to negative, and vice versa, with exaggerated efforts. It was also observed that Ernesto is very impressionable, that is, he is easily influenced by others or by circumstances. Upon assessing his current situation of addictive dependency and institutional dependency, his degree of dependency is deemed moderate to severe, especially if we compare our findings with those reported in the evaluation made by his caregiver.

RICARDO: “I HAVEN’T BECOME INDEPENDENT”

Presentation

Ricardo is 47 years old, up until a few months ago he lived with his mother. He is the second of four children. His hospital record is long. From outpatient care services, he went to the long-term care residence unit. He has been diagnosed with *Compulsive Gambling with a Personality Disorder*.²⁶ Currently, he is visited by his older brother.

Familial Context

I was born in Cuenca but I came to Madrid when I was three years old. I’ve always been with my mother, my father died a short time ago, about a year and a half or so ago and I have problems at home because my mother is very large and she can’t do things anymore, she can no longer attend to me and I’ve had problems with my brothers because I’ve argued with my sisters-in-law and not one of them talks to me, and my mother can’t come, she has to call my brothers on the phone so that they come to see me. Every once in a while they listen to her, other times they don’t. This weekend they were supposed to have come to see me but they didn’t come, I don’t have any money, or cigarettes or anything, and I don’t expect to get anything else...

There’s four of us, brothers... and I’m the second. They are all married, except for the eldest who is living with someone, they’ve been together for many years but they aren’t

²⁶ Pathological gambling is a psychological disorder that involves the overwhelming need to gamble, even beyond one’s own will not to do so.

married. He had a son with that woman but... I mean with his partner, but he died, he suffocated... I don't know, he couldn't have him...

My mother lives alone, my brothers are all independent and out on their own... except for me...

My father died a year or so ago... from an operation, he had stomach ulcers, and he also had chronic hiccups and so he would put his fingers down his throat to get rid of the hiccups and one night he got really sick, throwing up everywhere... they took him to the hospital and opened him up here [he points to his stomach] to get a look at his ulcers and because of a pain that he had in his chest and he had an obstruction in his aorta, they wanted to do a graft but they couldn't and he didn't make it out of surgery.

My mother is 74 years old, I have some issues with her because she has a short temper, but... and she spends a lot of money and she only gives me a little... and I don't have any resources and I can't become independent and my brothers don't talk to me, they're fed up with me...

I'm here because my brothers think that my father's death was my fault, or at least that I caused it... that I would ask him for money, that I didn't do enough to do well by him, to get along with him... but, in fact, my father would give me money, I would ask for it... The thing is that I had a problem, I'm a compulsive gambler... I would spend all of the money on the machines and my brothers would get angry, but he who really made my father's life difficult was the youngest who is thirty something years old, he did what he wanted, he ordered my father around... he kicked my father out of a business that he had, and he made his life impossible. I would go to see him and I would say to myself: 'well, now he's angry,' because he has a very bad temper. He's married, he's been lucky because he has a wife who works, they've got houses, the two younger ones, the two who are right after me both have houses, their two cars... each of them, my father helped them out a lot but he couldn't help me the way that he helped them...

My mother wants to get me out of here, my mother wants me to go back home.

I lived in Getafe, I have three nieces and nephews. I haven't seen my youngest niece in years, the one... the niece whose name is Sofía I haven't seen in a year, they don't let me see her... my brother... She's the youngest one's daughter, my mother doesn't talk to him, and he doesn't talk to me either and that's just fine... he has a really bad temper, he looks at me with a look of... and he gets really tense, he kicked me out of my father's businesses, he says that it's all his and I always have to go out and fight with him...

The one who comes to see me is my brother... the older one... the third brother, he used to worry about me a little... but ever since I argued with his wife he hasn't had much to do with me... he comes because my mother sends him...

Since my father died... a friend of mine once said to me that... that what my brothers wanted was to stick me in a place like this forever and leave me with nothing, no inheritance, nothing. That that was what my brothers wanted to do... well, not my older brother, no; the two that are working in the shoe store...

The two most important people in my life are my older brother and my mother. I got along well with my father, he would insult me but he always gave in. I would say: let me have ten euros on Sunday, and he would say: 'son of a bitch! You are just going to go and spend it on the machine... take it but don't come back looking for more!' He would give me money but I would have to stay out all afternoon, or else he wouldn't give me any money. But he was a good man. He would get angry because he was partly right...

My older brother was here recently to see me. The thing is that he is paying for an apartment and he couldn't give me any money. I remember one time, back... in the

beginning, he gave me a carton of cigarettes and 50 euros... when he couldn't afford it, the older one, who is paying for the apartment, he's paying for Internet, he's paying for a lot of things. And now it seems like his wife is helping him out because she didn't work and now she's helping him out a little. She's Brazilian, but her parents are Spanish...

Relationships... yes I've had them, but she moved to a different neighborhood and I didn't hear from her after that. The first one was when I was 18 years old, she was the one that moved away, and then I had another one afterwards, when I was 30 years old, she suffered from depression and I met her in the center for compulsive gambling... I met her there and we started to go out and one day she got really sick and she took a bottle of pills and she killed herself. Her name was Marisa, she wanted to marry me... but no, she killed herself.

Social Context

I have friends, I'm an easy-going guy and I make friends easily... but friends who are sick here, like I am, and outside I have just one friend, that's it... and I treat him like a son. I tell him: 'you are like a son to me'... because he had an affair with a girl when he was 17 or 18 and he has a son out there but he never recognized him as his own...

He's my neighbor, I used to go out with him to do some odd jobs... I taught him and I would say to him: 'you have to find yourself a trade.' Now he's in gardening. He asked me if he should do a gardening course if he didn't find work. I told him: 'well... do the gardening course and get specialized.' He's a little... he's not very... he's not retarded, he's just a little slow...

He has a slight disability and I tell him: 'get yourself into that... even if you don't earn that much.' Because he earned about 380 euros a month, but he's learning the trade, they teach you the trade and you learn a trade. But his father has already spent a million pesetas on him and he didn't get it ... And he's often said that he's spent lots and lots and lots of money, but this time... he got it on the third try [he is referring to his friend's driver's license], they gave it to him and now he wants a car and well... That's my friend, the neighbor... the one I have on the outside, out of here, the one who comes to see me.

Health

I've been here now for two months... it will be two months, since August 2nd... but I've been in and out of here for 18 years. I used to be in HB, but now that there are problems at home, since my mother is no longer well and she can't do things, she can't do anything, they've admitted me into... to R3. Before, I was... in for three months, for 15 days, for two months, for a month... and then I would leave, when my father was alive... but I can't anymore.

Before coming here they operated on my neck, I had a cyst, a tumor in my neck [he points to his scar] and I came out fine, nine days later I started to smoke and stuff... very good, very good. Then I got a bump here and they operated on me at the Paz... that was in June.

I I used to come and get myself admitted and then I would leave because I had episodes of schizophrenia. I have residual schizophrenia. When I had episodes, I would come here to the emergency room and I would get myself admitted for two, three months... depending ... and then I would leave. But, I might not this time, I might not... leave because well... since my mother is dying and she is the only one who can help me, now I won't get out of here. My brothers have their families and do their own thing.

I gambled a lot, I had a really bad time when I got myself knee deep in shit... to the very bottom. Well it's been... when my father was alive, about three, four or five years. Well... I've been gambling for six or seven years. Gambling has caused all of my problems. The slot machines... Compulsive gambling.

Work Experience

Yes, I've worked but without insurance. The amount of time I've worked doesn't reach five years. I've worked in shoe repair. My father always worked in that, he had a really big shoe store. Heck... he still has it, my brothers work there and because of my younger brother, I can't be there... because he can't stand me and we've already ended badly, we've ended up in fights and everything...

When I had money, I put it all into my house. I wasn't smart because my brothers saved all of their money, they put it in the bank and I bought furniture for the house, I bought television sets, I bought everything and I had it all at home, I wasn't smart.

When I get out of here, I want to work somewhere because I get a subsidy, more than 149 euros, I don't know if... they let me, that's the only thing that I have. It's a subsidy from the Community of Madrid, I don't have a pension... I have that aid and nothing else.

And working in the street, I have to make an effort and go with my neighbor to help him and then he gives me money and that's how I get by...

I used to go out to work in construction with the neighbor, doing remodeling, cement work, electrical wiring, doing things, lifting materials... Yeah! Before being admitted to the hospital I worked... in temp agencies... I also worked as a supply-boy in a warehouse. Years ago I worked with my brother, he had a business, but he gave that up and went to work in another shoe store like the one my father had, one that did shoe repair. I was with him [he is referring to his brother] for many years, then later on he gave up the business because he made a lot of money... a lot of money, he had a lot of customers, but it all went towards paying the bills because he paid a hundred or so thousand in the store's rent, and then the stock, and then for a salesperson that he had working for him and the community surcharges... and then they installed air-conditioning and they raised the surcharges by twenty thousand pesetas... every month, and he couldn't make ends meet. He worked all day long, he was there all day and then he didn't get anything out of it, he paid a lot of taxes, he's still paying taxes. He lives in X [he is referring to an area of Madrid], and he still has a thing with the town hall and every... almost every .. about every two or three months he pays 50 euros, he has a debt in back taxes. That was, it was eight or ten years since I was with him. He had another trade, he was an electrician, and he's out on his own ... He doesn't ask anyone for money, he's independent, he's with his wife...

My mother has a good pension... she gets 277 euros because my father was self-employed, so that's what they give her. The thing is that my father has businesses, he has a store and a shoe store and when its rented he lives off of the store and when it's not rented he lives off of the shoe store. That's why she's with them a little... and why she's a prisoner to them and why: 'when are you going to go and see Ricardo?'... 'When we can'... and I was expecting them to come to see me over the weekend but then didn't come to see me.

Training

I got my primary education diploma... but I would have liked to have learned a trade, because in construction I would learn little by little...

Over vacation, when it was the festivals of Sebastián de los Reyes... with the bulls and

all that stuff... I got away from here and I was at the parties and I spent two days there... I've run away two times in a row... I did! Because it really gets to me, being held up here.

During rehabilitation, they make us summarize the newspapers, do word finds ... stuff like that, do crossword puzzles... which I'm very good at.

At home, I would do the grocery shopping... everything, go to the market, go for the bread, for the milk... everything. My mother's legs are very bad, she can hardly walk. And now she's very ill and my brother tells me that once my mother dies, I can forget about them.

Inner Life

What usually happens is that I get very nervous when they give me the pills. You see I needed achineton for the... and the specially prepared injections that they give me... they didn't used to give them to me at first because they said that it was enough just with the transilium. And then for a month I suffered a lot, I had to take a shower every... all the time. In the morning you can shower and then in the afternoon they let you do it too from five to seven, but I would go and do it, and I would shower because I couldn't stand the nervousness. I was really a mess, it was a really bad month and that's why... I was, it was too much for me and I left. I went to the street. Now they're giving me treatment... the doctor, and I'm better... much better.

I'd had a lot of faith, but I don't have much faith now. I've had faith and I believed and now I don't have a lot of faith. Sometimes I go to mass... every now and again, Saturday or Sunday I usually go to mass... but not as much faith as I had before.

Current Life

Well, here... I shower, then we have a lot of breakfast, then we go to say good morning... we do group therapy and then they hand out our cigarettes and at eleven we have group therapy here, in the emergency room... we go to therapy. From eleven to twelve or twelve to one... depending... Then we come back, we eat lunch and they open up the rooms for us to take a nap and stuff... It's a routine... but, oh well, you have to do it.

I prefer to be in my house with my mother. She came once, my brother brought her, she came to see me, she brought me clothes... I've been here for two months and I've run away twice, they threatened me, 'that if I didn't go back... that they would call the police to have them bring me back' and my brother, my older brother brought me back...

Sometimes, with my older brother... I get along with him or I don't, because he also comes because my mother tells him to. He gets here, he deposits money in the account and he leaves and he doesn't even say good-bye to me... I argued with my sisters-in-law, I argued because of the problems, because of the gambling, in my house, not in their house, in my house... my mother's...

I'm taking an injection and a half of novocate and another of achineton, two and a half new injections that they are also giving me for... they did some tests and I came out positive for the... they are vitamins, I have to take them for nine months...

In the afternoons I like to go to the gym... but not right now... I'm going to rehabilitation because I hurt my leg, it's an injury that I got when I was a kid... and the doctor says that we'll see, that right now the therapy is more important... since it doesn't hurt me... When I walk a lot my leg gets weighed down and my legs hurt, they hurt on the lower parts.

When I get up in the morning, my stomach hurts me, my liver hurts me because I have

hepatitis C, that's why... I have a bland diet, no, one without any salt... I don't know if it's bland... a no-salt diet. I have really high blood pressure too...
On the floor that I'm on... no, I don't really like being here because there isn't a lot of hygiene, there are two bathrooms with two stalls and I think that you can catch diseases... There are more or less about sixteen people on my floor. I'm not comfortable on this floor, but oh well... I'm getting along and well... if the toilet is wet with urine, I clean it up and go to the bathroom, and I have stomach problems because if I don't smoke a cigarette or have a cup of coffee... I won't go to the bathroom well either.

Vision for the Future

My mother wants me to come back, we have a house in Cuenca... and the two of us want to go there. Being with my mother... but in the future, my mother is very sick because she has a sugar problem... she's got everything, she has high blood pressure, she's overweight and she doesn't listen... she eats, her head isn't working right anymore because she does things that... She spends her money on clothes, she has a... a man who goes and brings her clothes since... for her entire life, she's known him her whole life, she buys clothes for me from him... for everyone. She spends the whole day buying clothes and she's spent a lot of money too, she's partly to blame... but, well, anyway, it's her money, it's all hers.
Well... tomorrow I would like to become independent and live on my own and only talk to my older brother and not speak ever again to the other two... I only want to have a relationship with my older brother.

Comments on Ricardo's Story

Besides the information that came out of the interview, we see that the main focus of Ricardo's life is money, not only as a material means, but as a symbolic element that concerns him and his family unit. The value of money is turned into a conditional component in his emotional relationships, given the fact that it is a recurring concept in Ricardo's responses to any topic or question presented to him.

Pathological gambling is a disorder, not a vice. At first, it is hard to accept gambling as a disease and a pathological gambler tends to say that he/she can stop gambling on his/her own. Normally, compulsive gamblers try to fool themselves by denying the problem, even when they know that they are slaves to it and experience serious feelings of guilt. In Ricardo's case, a certain degree of awareness about his problem is noted through his apparent feelings of guilt and his social and work-related dysfunctions.

During his life story his recurring hospitalizations emerge, with his admittances to and releases from the outpatient emergency room services. The lack of parental figures, a deceased father and sick and elderly mother, worsen his profile of dependency and vulnerability. A diagnosis of "residual schizophrenia" cannot be determined, from which Ricardo states he suffers, since no detection was made of any kind of disorganized language or catatonic conducts, etc. However, the type of medication that he receives and a comprehensive analysis of his situation lead us to assess his current situation of dependency as severe. It is difficult to predict any progress he might have in that hospital unit, not because of the quality of the treatment but because of the patient's current levels of

dependency, as well as the minimal family involvement and lack of alternative services for medical attention.

TERESA, THE PEBBLE IN THEIR SHOE

Presentation

Teresa is from Madrid; she is 40 years old. The length of her hospital stay has been very prolonged: approximately ten years of admittances and releases. Currently, she lives in the long-term stay unit. It was not possible to determine the exact length of her stay because throughout the interview her speech was chaotic and barely coherent. Moreover, she was medicated at the time of the interview, which made it very difficult to understand her. Her clinical diagnosis is *Hysteria with Serious Personality Disorders*.²⁷

Familial Context

I'm 40 years old and I was born in Madrid. My parents are now sick and I would like to get well so that I can take care of them. Because my sister is sick, she could speak to the psychiatrist, but she's on leave with a medical disability...

Yes! My sister is on leave because of a sprain... I have a brother who is an attorney... excuse me. He did well for himself, he's an attorney in Telefónica... My father has helped us all. My father has a tyrannical type of personality and there is no one who can control him more than my mother... and the days that she doesn't go, it's incredible the amount of ... It's like...

I don't want to be a social parasite, I mean.... There are people who take things out of (...) fresh (...) new, a boyfriend and a therapy... that way, one will never get anywhere, no not that way... Spending it all on the first day... and then not having anything left. I want to cause a lot of ruckus in my family, they love me... You will honor your father and your mother! And (...) with their honor, with this... what do I do? What you both want me to do. They told me, yes, no, to talk it over... I want my parents to be proud of me because I've only given them upsets, tormenting their lives fifteen times [she cries], and they took care of me for twelve (...) I try horribly (...) by a bridge (...) but I can become a useful person, in spite of everything.

So they don't want me in my parents' house. So I'm the pebble in their shoe, they don't want to have anything to do with me...

They don't love me, they don't have any kind of ... They don't care at all if I go with this one or that one, as long as he lives with his mother, with his grandmother... excuse me...

My mother was kicking out my grandmother, they kicked her out. My grandmother, they sent her to a home for the aged and she protested: come on... please! Take me out of here, take me out of here... My soul aches. She is my angel that protects me from death (...) With so many things, I, I (...) well in the hospital they've done miracles with me (...) I fell on my feet (...) [apparently she jumped off a bridge] but I wouldn't say this to the sick ones.

Man! My father always helped out his own, he never spoke to me, more than he does now that his disease is... he doesn't limp anymore and he comes here out of pure... just enough to say he did, but he doesn't even wait five minutes to talk to me. He takes a

²⁷²⁷ Definition of Hysteria: mental disorder found within the group of neuroses, which is characterized by sharp emotional responses in situations of anxiety. The symptoms are extremely varied: simple tics, vomiting, amnesia, uncontrollable tears or laughing, paralysis, etc. Source: Glossary www.discapnet.es.

pack of BN, clothes and clothes to go after a boy. Can (...) a person? It's laziness. That is ideal (...) what happens is that you catch him, he's a real know-it-all, he's rich, but when they read the page that... he's got a thousand demons, he's not medicated, he's a mental case without any medication and to top it all off, he torments... my sister, my mother, he has destroyed us (...) until he dies... My father has been a tyrant, my other siblings managed to get their own lives together and that is what I want: get my own life so that I can fly.

I'm the one in the middle, but they don't show me any kind of affection and that is what I want, affection.

My mother has a bad foot, her feet are bad, so she makes the meals little by little, for example sweeping, she sits, sewing or (...) that's for sure, living at home without air conditioning is horrible.

They live in X [she names the street and the district in Madrid]. My father worked in the metropolitano... my father is from Guadalajara and my mother is from Ciudad Real.

My father wants us to take naps [she is referring to the visits to her house on the weekends], but taking a nap after eating makes you get really fat. I have serious nutritional problems because well perhaps (...) but I consider myself a normal person and in good company, good company, if I had a boyfriend it would be better...

Someone took away the couple and they laugh at you... and they say, how are you? (...) [what she says isn't understood and she cries]. I've had two loves in my life, one lesson in pain, he is a police officer in Barcelona. It was rape!... man, I don't know if it was rape (...) apartment (...) I know it was awful, I started to develop a crisis in which I detested men (...), women, so you don't know if you are bisexual. I've never had relations with women, my best friend is in love with me. A friend from outside of here, I haven't had any intimate relations with her... not ever, I don't like that. And Alfredo... I don't know what's the matter with me and men [she cries], they make me so upset that if I say no to them (...) if I say yes then they don't want it anymore. I just can't get anything of mine back. Men can't be gotten back...

Social Context

It seems like you are being a psychologist with me... yes ... but that smile that you give me, that's the smile that I would like, that I want to give happily from living, which the world gives me, the pills, the medicine. That happiness, transmitting it to all of those sad people, those who are unfortunate, who are sick, who need people to help them, who are sick, hungry, but... I go to the gym and I see them with the balls (...) and I tell them my name and – tss, tss! There isn't any water, and I go to get water, I give it to them, I give them (...) those soft ones (...) the old people... poor things! Which one of us will reach that age? I hope. (...) enough, so that we don't delay our life on coffee and Coke or by doing stupid things, but rather things that are necessary for society. Being useful to society.

You feel harassed here [she is referring to her interactions at the hospital]. They all harass me, cigarettes, 50 cents... What do I give you? What do I owe you? Coke? A coffee? ... It's disgusting! Nobody is anyone's friend. Nobody. First thing in the morning, I went down the ramp and a person as large as Nuria, she was all happy with her Coke and smoking a cigarette (...) well... it's time to smoke! To have breakfast and to sleep... (...) Then it's baths and showers (...) and you're there with (...) on the verge of an attack [she cries] with the quality of life (...).

I don't think anything about politicians... That's for them. Politics is for those who work among politicians and then they are all together and all friends. (...) managing the euro, the stock market, the euro, it's a game amongst themselves, a game. And the one

who pays is the day laborer... excuse me, the worker, excuse me...
What I don't like about society... drugs, cocaine, alcohol. Alcohol should be illegalized. I know about a lot of people who have come here, they've come because of drugs and I've seen a lot of people who are here because of alcohol, just because of alcohol. Pills and alcohol, it's not just about giving up the pills, you have to give up the alcohol, (...) drugs in bars, alcohol should be forbidden, forbidden. There is no reason why we should be poisoned (...) in a club, and being just as happy as I am with my coffee and my Coke ... and they, since I'm red [her face is indeed very flushed] and they think that I'm drunk. I'm just like them, except they are hooked on alcohol... of course, conflicts arise at the jobs, for the partying, twenty bucks, I mean (...) twenty bucks and we'll go to the lounge...
No one ... is anyone's friend!

Health

I've been, between the times they've admitted and released me, and my trips to the emergency room and then when they sent me home... ever since I was 30. Thirty cases filed away with various (...) family members (...). The great psychologist, X [she mentions her name] is trying to break me away from my parents for my own self-determination, but only for my own autonomy whenever it's possible, to do things for myself, besides... that is supposed to help me (...).
I've come to some conclusions ever since Doctor X, she's the one who's giving me incredible treatment, with a very well done diagnosis. (...) from the diagnosis. I'm medicated well, enough to talk to you guys (...). I talk nonstop. I don't like the guys here... change your clothes (...) it might be for hygiene, but I'm telling you that (...) me, I, to someone, me I, I'm staying (...) to someone. So if someone smiles (...) smiling. I want (...) you don't pray because they are laughing at you or they call you (...). You see that really does a number on you.
A lot, too much, they are killing me, between the cigarettes, the amount of money that it (...) for coffees, Coke and cigarettes, it goes above the standard. This can only be done (...) a person who is prepared to help one's fellow man. To help one's fellow man. I help out others because I know that maybe... I'm reading the constitution, there are laws and rights. I know a little about how the thing goes for workers and the right to work... Free development of one's personality, well that's not the case. They've never let me be myself because...
My problems are hysteria! It's as if you are acting like a psychologist with me [she laughs].
I try. I tell them to lower my pills and they don't want to. They don't want to lower (...) they only want pills, pills, pills... Please! Less medication, less or less transilium... not as addictive as the transilium and you don't talk like a normal person. Like a normal, civilized person...
I am a chronic suicide attempter and that's why I have to be in the hospital or in a supervised place. But I do know how to make people happy, at what time (...) of the day, I know. I can tell you that I just love the red that you are wearing [she is referring to a jacket that the interviewer is wearing]. I like your black blouse, I like black and red. I have circulation problems, my hands are cold and my face is very hot.

Work Experience

I've worked in graphic arts, in the hotel and catering business and briefly as a kitchen assistant (...) practically. I wasn't under contract because I was on a probationary period, that was the time that, that... Of course! And a few months later... You see, I

haven't been very perseverant. You've got to work on perseverance and I'm working on perseverance here, they are testing my perseverance here for a few hours. I've cooked at home; I worked as a kitchen assistant and I don't know what the kitchen is in this hospital. As for economic support, I only have my allowance. The pension. I would like to cancel my pension but the thing is that there are so many things that it's that...

Training

I finished COU [last year of secondary school], I didn't get the (...), but I got the top score in philosophy. It was oral... and everything that I know about philosophy... I'm an innate philosopher! I love the becoming of the situations of Heraclitus and 'The Dialogues of...', 'The Dialogues', of Plato. I like Aristotle, the ones before Socrates. I also like to paint... Art... I love it! After COU, they put me in here... And now I'm not good at anything else other than smoking and errands, and for... and there are times that my stomach hurts me, in spite of taking the medicine that they give me to coat it, it ... it hurts. I was in COU up until the third year, then I wasn't able to go to university because they didn't let me. I got fed up with family problems (...) knowing that I (...). I like to read... Yes! Emilio Salgari. Emilio Salgari which sometimes makes you laugh (...) the prince and the princess, the (...) and the marquise. The marquise, as soon as she had her coffee and her cigarette... How dreadful! I would like to be the duchess. (...) instead of being a slave to this situation that has lasted for more than a year, so long, ever since I was born. Changing and becoming a duchess, with faults. We all have faults, but... that's it, being useful in society. Since my house, I haven't made anything else but devices, from one side to the other, so if the sisters (...) I get lost... I haven't managed to get them to leave me alone even for a minute. It's harassment! Harassment by those people. When my parents come... Envy! Envy! And it's revolting. And in English! I nearly got the highest mark in COU. I translate any music in English into Spanish and I don't get bored. You see, I think in English.

Inner Life

There are times when my soul aches. My soul aches! When someone says that their soul aches, it means that I would like to be in my house, for my parents to welcome me, it's just that... I believe in God and I pray to him, I pray even though they might say.... That the social worker (...) Don't you think? I pray every day (...) my father (...) to the three... Because as they say... serenity (...) if you pray an Our Father, one of those miracles will happen. If you are really religious... superstitious, no! There is no Ouija board or anything of the sort.... Or lucky charms, or any bad luck charms (...) God is omnipotent and... and he's helped me many times (...) I believe in God and I pray...

Current Life

I don't like being here [she cries while talking] (...) five showers a day, I don't do that in my house, the water is in short supply (...) you've seen every little thing that brings you down into misery. I don't like it! First thing in the morning, they call for me at seven because of the problem that I have in my urine that... and it depends on the nurses (...) the shift (...) sometimes, I didn't

wet it today because at five thirty that was the limit, that was the limit... [she usually wets her bed while she sleeps]. Yes! Because I take too much of this [she holds up a bottle of water]. You might have a piece of licorice and you drink water and what do you get, you get filled up! [she had a piece of licorice in her mouth and was carrying a bottle of water]. After getting up, I dry myself, I put something on, whatever, if they tell me it's cold, it's hot... And I put on the first thing that I see. There are times that I look horrible! I've never had the chance to buy myself clothes. Even if the doctor says (...) one day all by myself, with my money.

Yes, I have a lot of money in the bank and ... knowing how to use it. The thing is that here we don't know how to handle money, nobody... Some have enough to throw around and others are short on it ...

I have money.

I often go out on my own with my friends, they go out on the prowl, they think they can pick somebody up or find a mate. Do you like this ...? (...) I mean I am 40 years old, I've already learned, this life has already given me a lot of years... They've toughened me up.

I go to Retiro... sometimes to buy kiwis (...) What do I do outside of X's surroundings? [she is referring to the neighborhood in Madrid where her parents live]. That my father stops putting me...

My mother worries me, the fact that I can't help her because my father doesn't want me to go. He makes it worse. He says that he does what he can, that he does the shopping (...) his knee hurts him.

Well, one day I might go to the book binding workshops (...) in the afternoons I would go out with a friend (...) I would do what she did, she would get on a bus, reading a magazine, she would have a decaffeinated coffee with a muffin and she would come back, ever so calmly...

Today, for example, in therapy... I won't even tell it. An incredible, long walk! I didn't know whether to smoke or to take a shower, all of my bones ached, all of them... I don't know if we did three laps. On other days, we read the news, the newspapers...

My obsession is that I will be fat. I'm a victim of...of aesthetics. Today I was lazy but I am a good eater, I like the good things in life, the good things make me happy. Even though sometimes I do things like taking a shower without permission. The thing about the shower is the most interesting (...) all of the women in the shower. Yes (...) to Freud, if I had had a stable life... but (...) where do you find it, where do you find friends (...) Look at how they look...

Vision for the Future

It's that I (...) sick (...) social reorganization. Excuse me [she pauses]. From rehabilitation where the nurses are. I could occupy a spot at another place, changing completely (...) and working. I see myself as an aid, I've learned, I have my notes... Getting a week of learning, isolated...

If they managed to get me on less medication and to be in my room all day with clothes, except for when I have to run errands, my own errands... going to take a competitive examination to become an administrative state worker for example. At the day center they are going to offer, they are going to offer computer classes. The thing is that you have to leave here, that interests me... It's like gold and wool. Leaving, leaving (...) everything about my illness, the digestive system, the esophagus, reflux, hernia and everything else... It would be two days a week, the interviewer will ask you what you want to do and things like that. I would like to... I (...) singing and dancing (...) on television...

Comments on Teresa's Story

Undoubtedly, Teresa's story is very complex, both because of the logic in her responses and her pathological profile. The literal transcription of her interview needed to be provided for two fundamental reasons: on the one hand, to facilitate the reader's access to the material in a relatively understandable manner, which involved structuring her life story section by section; and on the other, to maintain and respect the speaker's form and patterns of speech.

However, given that the main objective of this research study is to analyze the personal views of those interviewed towards dependency through their own oral discourse, the path is obstructed in the cases that involve incapacitating mental illnesses, in which said discourse is clearly affected. In Teresa's case, we observe episodes of psychological imbalance, her language starts out as understandable, reflecting an appropriate awareness of reality; however, little by little, it becomes disorganized. Her discourse becomes increasingly corrupted by pathological subjective experiences and her fantasies, which disconnect her from the outside reality. At the same time, her behavior is disoriented and unsatisfactory, and her personality is very disorganized. Somatic types of complaints appear frequently, as do mentions of sexual dysfunction and feelings of surprise towards herself and her environment, along with fantasy-like and simulated feelings. This symptomatology would appear to indicate a profile of hysterical neurosis with a high degree of imbalance.

On the other hand, her current state of vulnerability reflects significant difficulties in terms of developing her personal autonomy, since her emotional, relational and social conflicts are still so latent that they hinder her from making use of her other inner resources like her intellectual level and her ease of learning. Added to this is her dependency on hospital care, since she does not have emotional support or family supervision that she can rely upon in the outside reality. The long periods of hospitalization and inexistence of intermediate mental health networks, worsen her current situation even further. From this perspective, the hospital not only treats, but also encourages her implicit vulnerability. Taking into consideration her current situation, Teresa's degree of dependency is moderate to severe, making it unlikely to foresee a positive future.

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