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# Families Caring For Mentally Ill Patients: A Qualitative Study In Rural Nicaragua

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**ABSTRACT**

**Introduction.** Because of the enormous lack of mental healthcare in Dario and Terrabona, the NGO Prosalud wants to create a community- and family- based network to improve mental healthcare in this region. In order to align this program close to the local needs, this study aims to provide insights into the lives and needs of families with a mentally ill family member.

**Methods.** A qualitative research design was applied. The researcher accompanied the Prosalud health workers during their field visits in the different communities around Dario and Terrabona for two months. Eleven in-depth interviews were conducted with family members living with a mentally ill patient. Data was analyzed using thematic analysis approach.

**Results.** This study revealed that families caring for one or more mentally ill family members lived in tough conditions without much prospective. Many of these families, already living in remote areas, lived secluded from the communities and tried to hide their situation by completely isolating their mentally ill family member. Moreover, families felt they did not receive sufficient information from professionals about medical treatment or dealing with a mentally ill person which led to ignorance in the caregiving families resulting in deplorable situations aggravating the patient's disease. The families themselves experienced severe burden with physical, emotional, mental and financial impacts.

**Discussion and conclusion.** This analysis showed that within mental health the most important and urgent need is a very basic one: that families with mentally ill family members can abandon their isolated place in the community and live in more dignified conditions. Therefore, more emphasis is needed on reducing stigma and providing information about how to deal with a mentally ill family member and disapproving unacceptable behavior, like isolating or beating the mentally ill. Mental health professionals, Brigadistas and self-help groups for families can contribute in achieving this goal.

## Introduction

*'Without mental health, there can be no true physical health' (p.3).*

This well-known premise was stated by the first Director-General of the World Health Organization (WHO) in 1953 (Kolappa, Henderson & Kishore, 2013). More than half a century later, Kolappa et al. (2013) state that there is strong evidence clarifying the bidirectional relationship between mental illnesses and physical health outcomes. In 1978, the Alma Ata Declaration on Universal Health Care paved the way for efforts to incorporate mental healthcare in primary health care to reduce the burden of mental illnesses in low-and middle-income countries (LMIC). More recently, new programs with a focus on mental health have been developed in the Mental Health Gap Action Programme (mhGAP) and the the 65<sup>th</sup> World Health assembly resolution on mental health (WHO, 2010; WHO, 2012). Despite these efforts, the reality for people with a mental health disease has hardly changed across many LIC (Jacob, 2017). Fourteen percent of the global burden of disease is attributable to mental, neurological and substance use disorders and almost 75 percent of this burden occur in LMIC (WHO, 2010). In addition, it is the poor who are disproportionately affected by these disorders. According to the Pan-American Health Organization (PAHO)(2009) there is a higher risk of suffering mental disorders for people who live in poverty, who are less educated and for those who face debt and hardships in acquiring basic necessities. In turn, the disabling effects of mental disorders impair the ability of people to seek for and preserve productive employment (Patel, 2007; PAHO, 2009).

Nicaragua, the second poorest country of Latin America, is one of these countries facing serious mental health needs and challenges (Sapag et al., 2013). Literature shows that the mental health situation in Nicaragua is complex and has been influenced by a history of natural disasters and political struggles. A dictatorship by the Somoza dynasty until the 80s, followed by civil wars and oppression by the US in the 90s and several earthquakes and hurricanes left individuals and their families with lasting psychopathological and psychosocial wounds (Van Der Geest, 2005; PAHO, 2009). Statistics show that over one third of people with a mental illness do not receive mental health care from either specialized or general health services (PAHO, 2009; WHO, 2010).

According to Van der Geest (2016) the limited care is mainly related to the way healthcare is organized. From the total budget for health care only 1 % is spend on mental healthcare and 90 % of this budget goes to the only psychiatric hospital in Nicaragua, based in the capital Managua. This concentration of mental health resources reveals a huge inequity in mental health distribution, with barely any public mental health

care service in the whole rural part of Nicaragua (WHO, 2011; Sapag et al., 2013). The scarcity of these public mental healthcare resources seems to be leading to few possibilities for mental health in medical education. Only 2 % of the educational programs in medical education are devoted to mental health (Sapag et al., 2013). Even the nurses who work in the psychiatric hospital in Managua receive only general medical education without special attention to psychiatry (WHO, 2011; Van der Geest, 2016). Consequently, general medical doctors as well as nurses have little knowledge about mental health. Besides, many doctors work in their own clinics next to their public work since the wages in the public institutions are low in comparison with the private wages (Van der Geest, 2016). The same applies for the field of mental health with many psychiatrists and private clinics in Managua, where hospitalization is so expensive that only people from the highest social class can make use of it (Van der Geest, 2005). This seems problematic, since most poor people have no health insurance (Sequeira et al., 2011). The public insurance system provides mandatory health insurance for salaried workers in the formal public and private sectors, their spouses and children (PAHO, 2009). However, in the rural areas most people work in informal sectors making the insurance packages not equally distributed, and literature points out that the insured demographic profile is dominated by urban non-poor populations (Angel-Urdinola et al., 2008). Consequently, for people living in rural areas, it seems hard to receive mental healthcare since resources are unequally divided, facilities are out of reach and the quality of existing mental healthcare is questionable. The few alternatives for these people include consulting a local unskilled primary healthcare worker, or consulting a traditional health practitioner (Patel, 2007). The traditional healthcare practices are sometimes doubtful and in some cases, imply the abuse of human rights: this was tragically demonstrated by a recent event in a Managuan church where a mentally ill woman was burned to death to get rid of the demons inside of her (Patel, 2007; NoticiaCristiana, 2017).

Although the Nicaraguan mental health care system has its shortfalls, there have been some useful developments. In 1981, The Nicaraguan government started a program with informal health care workers in order to reach remote communities over all of Nicaragua (Scholl, 1985). These communities generally consist of approximately 40 households living closely by each other and sharing some facilities such as a church and a local store. The Ministry of Health provided health education to volunteers from the community, the so-called Brigadistas, in order to provide primary health care in these communities. The Brigadistas were educated with the idea of stimulating local community involvement in health and as a means of overcoming rural health manpower shortages (Scholl, 1985).

Although the Brigadistas' focus has not been mental illness prevention, it appears that some organizations are trying to involve these Brigadistas in primary prevention and detection of mentally ill community members. An organization that has involved Brigadistas is the Non-Governmental Organization (NGO) Prosalud, founded by the Belgian doctor Toon Bogaerts.

Impressed by the total lack of healthcare in the region of Matagalpa, Dr. Bogaerts decided to provide aid by building a sustainable healthcare network for the communities in this region. Prosalud manages several projects in Dario and Terrabona: the maintenance of two primary health care clinics, a social pharmacy, organization of self-help groups for chronic diabetic patients, therapy for children with a disability and working in alliance with the Damian Action in the battle against tuberculosis. Although Prosalud focused mainly on people with physical health problems, it was no longer possible for the Prosalud-team to ignore the alarming lack of mental health care. In 2016, this led to the start of a new project named 'Armonia Mental' in collaboration with Edward Verbruggen, a Belgian psychiatrist. This project, still in its infancy, attempts to provide support to people with severe mental health problems in the rural region of Ciudad Dario and Terrabona. They want to provide affordable and community- and family-based support for both the patients and their families because they receive many signals of suffering within families and there are many needs that are not fulfilled (T. Bogaerts, personal communication, May 17, 2017; Murthy, 2003). Murthy (2003) studied the power of family interventions in which he states that '*developing countries have a unique opportunity to build mental health programs on the strengths of families*' (p. 3). His study shows the importance of insight in the families' resilience. Prosalud wants to use these insights in building effective interventions. In order to realize this, I will conduct research about what is happening within the families living with a mentally ill child, brother, sister or parent.

### **Theory**

Literature shows many studies and views on how caregiver families live and what their needs are. Murthy (2003) believes there are three requirements needed for families to take up the important role of efficient caregiver. Firstly, families need support from mental healthcare professionals in order to achieve the skills of care, crisis support in emergencies as well as emotional support to meet their own needs and maintain cohesion of the families. Secondly, the state should support families financially in order to give them basic support and help them to form self-help groups. Thirdly, professionals should

support these families by acknowledging their strengths and recognizing their important role in caring for their mental-ill family members (Murthy, 2003).

For the exploration to these families' needs, I use Maslow's theory (1954), the hierarchy of needs, as a theoretical guide to describe their needs. Maslow postulated a hierarchy of human needs consisting of five levels: physiological needs, safety needs, social needs, self-esteem needs and self-actualization needs. The first layer includes the fulfillment of their most basic needs like water, food, breathing and homeostasis. Next, I will explore their feeling of safety, including shelter, security, family, health and employment. The third level includes social needs involving family, friends and the community. Fourth is their esteem, achievement, respect and confidence. The final level is self-actualization: the realization of a family's full potential. Although this theory received a lot of criticism, it can serve as a reference to discuss and explore the obstacles many families in rural Nicaragua face when trying to provide care for their family and mentally-ill family members (Hofstede, 1984; Kenrick, 2010).

This research will explore how patients with a mental illness and their families live. I want to create insight in the way families live with their mentally ill family-members. I want to know how families take care of them, but also how they live their own lives. What is important for the families and what should change according to them? The aim is to understand the individual and familial perceptions and needs in mental health care in order to create a community- and family- based network aligned with these needs to improve mental healthcare in this region.

### **Methodology**

I started this study from the idea that, to gain insight into the lives of persons with a severe mental disorder and their families as main caregivers, I should focus on understanding how these people live. In order to study these families' perspectives and needs, I accompanied and observed the Prosalud team during their field visits to the families living in different communities around Dario and Terrabona. I 'officially' interviewed 11 families with one or more mental-ill family members. Four families lived in Dario, in a more urbanized context, and the other seven families were living in the mountainous region of Terrabona. The ages of the patients ranged from 17 to 55, with the exception of an 11-year old whose family was included in the study because his mother had a mental illness too. Three families had more than one mentally ill family-member. Because the patients were not very communicative, the interviews were performed with the main caregivers and describe family stories about living with the sick family member.

In some situations, it was also possible to have a short informal talk with the patients themselves. Table 1 provides an overview with the main characteristics of the families and their mentally-ill family members. All names provided are pseudonyms.

The local project leaders, a physician and a psychologist, always accompanied me during the interviews to introduce me and overcome the language barriers. They informed these families about the study and asked them to participate. To allow for diversity in the families, I asked them to recruit families with the following characteristics: variety of neuropsychiatric disorders, living in remote communities and in semi-urban districts, male and female caregivers, few and many family members, and severe as well as mild manifestations of the disease. In general, the participants took part in this study without hesitation: they welcomed the opportunity to talk about their experiences of living with a mentally ill family member.

The interviews were semi-structured and presented comparable topics to all participants, but were open enough to go into depth on the specific experiences and circumstances of the individuals' families and family members. Themes such as involvement in the community, professional support, needs in mental health care and treatment adherence were discussed, but participants were also encouraged to talk about their everyday experiences with the mental illness in a broad sense. The interviews lasted 30 to 60 minutes and were tape-recorded and transcribed verbatim. I analyzed the narratives by identifying interesting theoretical concepts from other studies on mental illnesses in a poverty context, such as the isolation these people live in, the role of the community and family caregivers providing care, and the considerable burden on the family members.

I identified the themes related to these concepts after reading and rereading the transcripts. I searched for similarities and differences at the individual level as well as at the level of the families.

Table 1. Overview of interviews

Region	Patient	Age	Diagnosis	Family caregiver
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Terrabona	Jorge Prado	30	OMD associated with epilepsy	Father
	Steven Prado	40	OMD Intellectual deficiency	
Terrabona	Miurel Marques	33	Schizophrenia	Mother and sisters
Terrabona	Jose Prado	55	OMD associated with epilepsy and probably autism	Sister and mother
Dario	Mara Lopez	17	Schizophrenia	Mother
	Sergio Lopez	25	Bipolar disorder	
Dario	Claribel Rosales	48	Schizophrenia	Mother
Terrabona	Alberto Prado	42	Schizophrenia (and probably OMD)	Mother
Terrabona	Anry Prado	30	Schizophrenia	Mother and sister
Terrabona	Enrique Morales	36	OMD associated with epilepsy	Mother
Terrabona	Davide Manzales	27	OMD associated with epilepsy	Mother and sisters
	Vincent Manzales	30	OMD associated with epilepsy	
	Emilio Manzales	35	Intellectual deficiency	
Dario	Diana Lopez	42	Schizophrenia (and probably OMD)	Sisters
Dario	Roger Travez	11	Schizophrenia	Brother/Son
	Myriam Travez	52	Schizophrenia	

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*Note.* OMD: Organic Mental Disorder

## Results

While analyzing the interviews and field notes, three general themes could be distinguished. Firstly, isolation was perceptible with both the patients and families due to



their place of residence but also their way of living. Secondly, giving care in a family context was not always self-evident, the family-caregiver often lacked information and support from professional caregivers. Finally, family caregiving entails a burden on these families on many different aspects: physical, emotional, mental and financial.

### **Patients and families living in isolation**

All 7 families living in Terrabona lived in an isolated location. The communities they belong to were hard to reach or escape. Most people in these areas were small-scale farmers and landless farm workers. Some families tried to combine both agricultural and other income-generating activities on the farm. Although Dario is a more accessible town because of its situation close to the Pan-American highway, the surrounding communities are still hard to reach and people face many constraints, including physical isolation, fragile ecosystems, difficult access to land and other natural resources, low productivity of soils, obstacles to market access and lack of public services such as education, health and legal services. For example, the mother of the sick 6-year old Jose told me that the only way she could reach health care for her son, was by walking for 5 hours while carrying her son. She had to wait for her husband to come back from work to make this long journey, although nightfall was coming. Just like this woman, others told me they would not leave their communities unless it was necessary. Even for finding a spouse they would stay in the same community. It was striking to see that from the 11 families I interviewed, 6 patients shared the same last name, Prado. The professionals told me that genetic transfer and inbreeding could be an explanation for this circulation of mental illnesses in the Prado-family. I noticed that the families sharing their last names, often live in the same region but have no contact with each other and even have no idea about the existence of their ill relatives.

*'The doctor asked me if anyone else in my family had the same disease, but no there is nobody else like that. In my family, everyone is normal. She is the only one.'* (Claribel's mother)

The families did not visit each other or did not keep contact with each other, once more reflecting the isolation of these families. Many of these patients and families are socially isolated, experiencing a low level of interaction with others, even their family, resulting in feelings of loneliness.

It seems like the difficult accessibility of the communities and little communication between families and the community makes it hard to fall back on others when talking

about caregiving. Anry's family told me that they couldn't count on people in the community for help. Most people were afraid of him and rather avoided his family. I noticed that people in the mountains of Terrabona received little to no support from the other community members. According to the father of Steven and Jorge, this is simply due to the fact that everyone is minding their own business.

*'In this neighbourhood, we cannot ask anyone for a favor' (Anry's sister)*

*'Everyone has their own private life in this community, you know. People are busy with their own lives and try to keep out of other people's problems' (Steven and Jorge's father)*

In contrast, Roger and Claribel's families, who live in Dario, told me they could still count on the people in the community.

*'I trust my boy on the street, although he can be a pain in the ass I know that the whole neighbourhood will take care of him.'* (Roger's brother)

*'Her friends from the church committee pass by every once in a while to chat with her' (Claribel's mother)*

Many families did not include their mentally ill family members in any kind of activity or decision-making. During the visits, I noticed how family members decided everything for the ill persons, they even spoke for them without giving them the chance to express themselves. During the interview with the two brothers, 30-year old Steven and 40-year old Jorge, their father constantly interrupted and answered in their names.

*'Steven has not learned a single word since he was 7, he cannot talk or learn anything. That is why he stopped school so early' (Steven's father)*

As I noticed that Steven did understand me and tried to answer me, I asked the father to permit me to let Steven talk but even then it was very hard for him to stop speaking for his sons. Just like Steven and Jorge, almost all participants had to drop out of school or never went to school at all. Mostly because they had difficulties, were hard to handle by the teacher, or just did not want to go anymore. Roger, with very early onset schizophrenia, is one of these children who were too hard to handle to go to school.

*'It is impossible for Roger to go to school, the teachers cannot handle Roger alone, a whole class of kids next to him would be impossible' (Roger's brother)*

Roger never went to school and spent his days on the street corner with older teenagers and children that dropped out of school. Also, none of the patients had a job at that moment. Even inside their own houses, helping out was very rare for them. Claribel's mother calls her daughter lazy:

*'Yes, she can do most things. I mean she baths and washes herself but she likes to do nothing. But she was like this her whole life. That she likes to do nothing I mean, hahaha. She likes to delegate the work, but doesn't like to do it herself. She is very lazy' (Claribel's mother)*

In most families I felt that the patients, although tolerated by their environment, were mostly avoided. During the interview with Jose's mother, I saw Jose leaving the house. He went to sit on the neighbours' doorstep where he remained for more than an hour. The neighbours did not seem to mind, but neither did they ask him to come inside. Most families do not receive many visits because people are afraid of the 'locos', the crazy people.

In two of the families I visited, patients were locked up. One was Myriam, a 55-year old mother of 5 children and since a few years taken care of by one of her sons. According to her son, Myriam had very clear moments in which she was very independent, at other times she became violent. For example, whenever she is in the same room with her also mentally ill youngest son, Roger, she would try to kill him. Because of this excessive violence, they decided to lock Myriam up in a room. The only social contact she gets now is with her caregiving son, three times a day whenever he feeds her. The son was so afraid that his mother would hurt others, that he did not give us permission to personally meet her.

*'She is in the room next to us, but I am afraid she has one of her bad days and will hurt you. So I do not want her to meet you.'* (Myriam's son)

Another patient in detainment was Anry, a 30-year old man who has been tied up to his bed frame for four years because he had been acting violent during psychotic episodes. His mother told us that he has not been outside of that little room since then. She could not find another solution to Anry's aggressive episodes than to lock him up. Alone, she is not strong enough to handle him and she cannot count on the men in her family because they are never around. She tries to justify:

*'When Anry was in the psychiatric hospital for two weeks, he got beaten up and other patients stole his food. I found him starving and full of bruises so decided to*

*take him home. Here, at least he does not get beaten and he gets something to eat. In the hospital he would be locked up, get beaten and starve from hunger. (Anry's mother)*

When I met Anry, he was lying on his bed without giving any response. He was clearly suffering, obese and gloomy. In both families that decided to force their ill relatives into captivation, I could sense a sense of hopelessness and despair.

Many other families isolated their relatives too, but did not have to force them because the patients could not leave due to physical impairment or fear from other people. I have heard various stories about mentally ill women running away from home during a psychotic episode, to return few days later without clothes. Claribel and Miurel experienced something like this.

*'Claribel ran away from home two times, both times we found her 100 km further down the road without any clothes' (Claribel's mother)*

*'Years ago, Miurel ran away from home and returned completely naked the next day' (Miurel's mother)*

Since these incidents, Claribel and Miurel's families try to keep their mentally ill family members inside of the house, for their own protection.

**Conclusion.** In the context of families living with a mentally ill family member, isolation is present in many ways. Families living in remote areas only leave their communities when necessary. Also within their communities they have only little contact with other families or community members. The mentally ill relatives are even more isolated, according to different families there are different reasons: the families want to protect the mentally ill from fear and stigmatization in the community, or families want to protect the people in the community from the violence of the mentally ill.

### **Care in a family context**

Providing care to a mentally ill person comes with a lot of responsibilities that are not always self-evident. The families were often clueless when talking about the disease and treatment of their ill family members. This emerged from the interviews. Whenever I asked a family to describe what illness their relatives had, they had difficulties describing what disease they were suffering from. They could only guess for a cause and search for a way to live from day to day with their mentally-ill family member. Miurel's mother explained:

*'It is that she has problems with the mind, control, she is confused in her mind. I don't know how it is called what she has' (Miurel's mother)*

Roger and Steven's father had similar experiences:

*'Sometimes it is clear that they are not perfect. But no one is perfect and they are just made like this. Their mind is just not normal' (Steven and Roger's father)*

All families had difficulties understanding how the medical treatment their ill family member received, worked. Miurel's mother told us that the doctor did not give any extra information with the prescription he wrote. After taking one pill, Miurel showed catatonic behavior (she did not move or react on external signs or showed any sign of motoric activity) so her mother decided to stop giving her any medication because she was worried. I asked her mother what kind of care they received. She answered that she hadn't received much care:

*'Nothing, only some pills here and there. And sometimes 10 pesos to buy some beans' (Miurel's mother)*

It was interesting to learn afterwards from my Prosalud companion that Miurel and her mother had seen several psychiatrists and doctors, but Miurel's mother never persisted in the treatment they gave her daughter. Alberto's family complained that the doctor did not inform them about possible side effects. Alberto's mother got angry at a psychiatrist for 'nearly killing her son', and decided to stop giving him medication after one time of side-effects.

*'The doctor told me to give 3 pills a day, I forgot which pills, but I gave one. I was sure my son was going to die after that pill. So, I was furious and decided to go to the doctor and I told him that I almost killed my son because of him' (Alberto's mother)*

Not only with medical treatment, but also in daily life the family caregivers had difficulties understanding how to deal with the patients. Diana suffers from a combination of epilepsy, schizophrenia and paralysis, most likely because she never received any adequate treatment. I met Diana lying spasmodic on the wooden slats of her bedframe, in her 'room' next to the chicken cage. Her mattress was lying outside, soaked by the rain that fell in through the holes in her roof. The smell of Diana's room was unbearable, it was a combination of humidity, urine, excretion, rotten food and chicken stool. Diana herself though, was very friendly, asking me who I was and how I was doing. She

answered all my question with a smile on her face but was clearly living in her own state of mind. Diana's main caregiver is her sister, who could not answer any of my questions regarding Diana's history of disease or current treatment. On top of this misery, Diana's other sister told me that Diana gets maltreated.

*'I always tell my sister that takes care of Diana that she should not hit her so much. But she just never listens' (Diana's oldest sister)*

On our second visit, Diana's finger was injured and when my Prosalud companion asked her what happened, she pointed at her sister. According to her sisters, Diana had not received medical care since 2010 and the doctor never explained the sisters on how to deal with her. The way this family treated Diana, led to a negative progression of her disease.

When treatment did not seem to work, Families often sought for alternatives like traditional health care practices. All interviewed families had consulted a 'curandero', a local healer. Many people were referred by their acquaintances and word goes around that they do good work. There are two curanderos in the region, one in Terrabona and another in Sebaco, a town 15 km further down the road.

*'The people say that he is a good doctor, the curandero' (Anry's mother)*

*'It is just an old man that doesn't do anything. But yes I took her once because people told me he was good and would cure her. One time, never again. I thought he would cure her but it didn't do so' (Claribel's mother)*

Although they were not shy about admitting going to these curanderos, they did not really go any further into the topic and often told me it did not work and they would not go again. Almost all were skeptical and disappointed since they did not see improvement. In all cases, the people held onto religion as another important source of hope. Even more when there was no other hope on improvement or better care. The church is the community's main place to bind and connect people from the community with other community members. During my observations and interviews, I heard many references to God:

*'Every day I pray to god to send someone for help and help our family, and here you are...' (Alberto's mother)*

*'I just would like to add that I am thankful to God, that he has brought us this far. I hope he will keep supporting us' (Myriam's son)*

A Prosalud health worker told me that the catholic religious communities keep providing support and encouragement to their members, even if they have mental illnesses.

**Conclusion.** Within caring for mentally ill in the context of families, the families stand on their own. According to the families, the professionals do not provide enough information about the side effects of medication, leading to poor treatment adherence in many families. Information on dealing with these mentally ill patients is also lacking, resulting in situations of maltreatment that only progresses the patient's disease. In the search for a cure, families often consult the local traditional health practitioner and if this doesn't work either, they turn to their religion.

### **Burden on the family**

My analysis made clear that family members of mentally ill patients take on multiple roles in caring for their sick relatives, which resulted in considerable burden on the family with physical, mental, social and financial impacts.

Some of the patients tend to be aggressive towards their family caregivers. Miurel's family was already living in fear for years because she can smack or slap them out of the blue. I visited this family three times, and every single time I noticed the little signs of fear of violence that terrorizes this family. Her sister's quick defensive reaction when Miurel walked past her, her old mother's dark blue bruises over her arms and legs, and the damage on every single loose item in the room. At the end of our last visit, Miurel pushed her mother on the ground. Another patient, Sergio, threatened his family with a knife and held his father hostage in his own house.

*'Sergio keeps his father as a hostage in our house. We are all afraid that Sergio is going to hurt him, unfortunately both the psychiatric hospital and the police are not helping us.'* (Sergio's mother)

These experiences obviously lead to a lot of stress. The family caregivers were coping with high levels of stress and emotional strain. The topics we discussed were sensitive and hard to cope with. All family caregivers had their own concerns, including their own health. Alberto's 70 year old mother shared her concerns:

*'Yes, it is a lot of suffering. I cry and he cries. When he gets sick or gets new convulsions. I feel bad. I stopped working to take care of him'* (Alberto's mother)

The high levels of stress even resulted into a mental illness for some of the family members. Anry's mother suffered from psychotic symptoms and got hospitalized for a week recently.

*'My nerves increased badly since his disease and I got all these kinds of weird stress' (Anry's mother)*

Sergio's mother told us that her daughter, Mara, could not handle the family situation and developed a mental illness herself.

*'Because she saw her brother like this, her nerves increased. I can imagine that isn't good for her. She is diagnosed with a bipolar depression' (Sergio's and Mara's mother)*

Another family burden is the stigma on the mentally ill and their families. Anry, the young man chained to his bed, is captivated partly because of outside pressure.

*'Someone from the government came here and threatened that we would receive a fine if Anry would endanger the neighbours again. The neighbours are afraid of him and tell us to hold him captivated, otherwise they will call the police' (Anry's sister)*

People are afraid of him and will do everything to avoid the 'dangerous crazy man'. I have heard many of these surnames during the field visits. 'Loco or Loca' (crazy person) and 'Malcriado' (someone pertaining to have bad manners) are some of the most common names that are used by these families. As a result, families often 'hide' their mentally ill family members.

The mentally ill persons often do not contribute in the household or finances of the family, resulting in an extra mouth to feed and extra work that prohibits family members to leave the house and go to work themselves. Although public healthcare is for free and medicines on the basic lists are free too, having a mentally ill family member is an extra financial burden for these families. Alberto's mother quit her job to dedicate herself to her mentally ill son. After many years, she became too old to take care of him herself.

*'My daughter quit her job and stays at home to care for both of us now, because I am too old to do it by myself' (Alberto's mother)*

Deprived of her daughter's financial aid, they now live from the little money one of her sons sends them from Costa Rica from time to time. Just like Alberto's mother, many caregivers are ageing. This creates concerns for the future and solutions are often hard to



find. I noticed that parents are the most dedicated caregivers, while the other family members like brothers or sisters, understandably, seem to want to focus on their own lives too.

*'I am worried, what will happen with her when I am gone.'* (Miurel's mother)

Some families still dared to hope for a better life without the disease, but most of them knew that there was little hope for improvement. Myriam's son, in his twenties and family caregiver for both his mentally disabled mother and half-brother, felt overwhelmed.

*'I do not know if I will be capable to take care of them for the rest of my life, since I do not think they will improve soon.'* (Myriam's son)

**Conclusion.** Families caring for their mentally ill relatives experience serious burden. Patients sometimes become violent and physically harm their family members. Situations like these create a lot of concerns and stress. Sometimes this even develops into a mental disorder for one of the other family members. Because they have only few prospects, it is hard for them to think about a positive future. Many of the family caregivers are old and struggle with their own health, resulting in more concerns about their relatives' future.

### **Discussion and Conclusion**

My analysis has shown that these families are experiencing many difficulties living with their mentally ill family members. To a large extent, this seems to be related to the context of poverty these people are living in: families are fighting a battle to survive, every day they wonder if they can afford food for the day, if their houses won't fall apart and if they will remain healthy. In fact, families with a mentally ill family member experience a double burden because not only do they have to fulfill their own basic needs, they also have to fulfill the basic needs of their ill family members since these patients are completely dependent of their family caregivers.

Families often do not know how to deal with the sick family members and force them into isolation, sometimes even in inhumane conditions. Because of this isolation, there possibly are many mentally ill silently suffering inside their houses without receiving

adequate treatment. There is a need to detect these mentally ill and give them the chance to live in more dignified conditions. In order to prevent the mentally ill from being hidden by their families, there should be a reduction in stigma and more openness about mental health topics.

In the event that patients do receive mental healthcare from professionals, it seems that the professionals do not take time to inform the families sufficiently about the medical treatment and its side effects, or about ways to deal with their mentally ill relatives. Many professionals work in their own private clinics next to their public work and only have little time per patient to search for a diagnose and propose an appropriate treatment. There seems to be no time to discuss this treatment with the family or the way in which these patients should be treated by them. Possibly, the non-capacity of these family caregivers to understand what mental health exactly means and how the treatment works, makes it even more difficult to inform them in such a short time. As a result of the families' ignorance, the patients' suffer from inadequate care, poor treatment adherence and emotional or physical maltreatment.

The families themselves are also suffering from physical and emotional burden of caregiving, which gets reinforced by the fact that most of them are ageing and therefore suffer from their own health issues. All these factors lead to a state of hopelessness in which many of these families live now. It is hard for these families to live their own lives and build to a better future, because they have only few prospects. If stigma could be reduced, the families would suffer less from these burdens and find better ways to cope with their position of caregiver. In this way, the development of new mental disorders could also be prevented.

Van der Geest (2005) conducted similar research on the impact of psychosis on families in Nicaragua, only 60 km from this research's study-site. The results of this analysis confirm her conclusions too and the similarities are striking: families hiding their mentally ill family members, the families' ignorance about mental health, the poor adherence to medical treatment, and the severe impact of a mental illness on the family.

Since her research, more than 12 years have passed. Does this mean that Nicaragua has not made any progress in the field of mental health during the last decade? Not necessarily. Van der Geest's research was performed in an urban environment, in the capital of the district of Matagalpa, while this research involved a more rural area in Nicaragua where mental healthcare might be lagging behind and mental healthcare professionals are out of reach. It may be interesting to carry out new research in the city of Matagalpa to see how mental healthcare in has progressed over the last decade.

The insights of this study can contribute to the improvement in mental healthcare in Nicaragua. For a start, mental health professionals could provide more support to families of mentally ill people. Professionals could help families acquire skills of care and crisis support in emergencies. They could also give them some emotional support in order for the families to meet their own needs and maintain cohesion of the families. Families could be seen as an added value in the treatment process of the mentally ill person.

Not only professionals, but also Brigadistas could be a strong asset to community mental health programs. Nicaragua has the advantage that Brigadistas can be deployed for health care, but they are barely used in the field of mental health. The state should acknowledge the importance of these Brigadistas in mental health and provide mental health training for them. This way, mental healthcare can even reach the remote communities. They could be staked in three functions. Firstly, they can detect mentally ill members in their communities and report these to the local health workers. Secondly, they can provide support to the individuals and family caregivers by following them up and frequently asking them about the situation. Moreover, Brigadistas can report cases of maltreatment and other human rights violations experienced by individuals with a mental illness. Thirdly, they can serve as an example to provide care and deal with mentally ill people in a healthy way. The Brigadistas can be an example for the rest of the community and reduce stigma and taboo by creating openness about mental health topics.

Another suggestion is to support the communities in forming self-help groups. According to Van der Geest (2016), there is small but precious evidence that self-help groups can work in this context. She started a small organization providing aid to organize self-aid groups for families with a psychotic family member living in Nicaragua. The project received several positive reactions from the community and was able to help several families to cope with the difficulties of living with their psychotic family member (Van der Geest, 2016). Self-help groups for families can help fulfill the needs of social belonging and esteem. If these family caregivers know there are other families struggling with the same issues, they will be able to talk about it and stop feeling so isolated. The ability to talk about mental health topics could also lower the stigmas involved. In Dario, self-help groups could be implemented relatively easy with only few resources, a room with chairs and some free drinks could be sufficient. In the mountainous region of Terrabona, it is somewhat more difficult because of the poor accessibility and the distance between communities.

Considering the results of this study, more emphasis is needed on providing information about how to deal with a mentally ill family member and to act consequent with unacceptable behavior, like isolating them or beating them. In families were

maltreatment is reported, there should be extra support and follow-up visits to ensure this family understands the negative influences of their own behavior.

As argued in the introduction, there seems to be no efficient mental health infrastructure in Nicaragua, there is not enough staff to care for all those who are in need, and medication is often not available. This analysis showed that within mental health the most important and urgent need is a basic one: that families with mentally ill family members can abandon their isolated place in the community and live in more dignified conditions. More educated mental health professionals, Brigadistas and self-help groups can contribute in achieving this goal.

### **Limitations**

During my research, I was able to conduct research in the direct involvement with families with one or more mentally ill family members in Nicaragua. I observed their behavior, emotions and needs and experienced their hospitality and honesty during the interviews, while being aware of our cultural differences. I shaped an idea about the everyday reality of these deplorable situations in which people suffering mental illnesses and their families live. I focused on the stories the families shared with me about living and dealing with their mentally ill member, their search for treatment and their role in the community. However, this research also has some limitations. Firstly, the interviews were all conducted in Spanish, and although I speak a fair amount of Spanish, the Spanish in Nicaragua differentiates on some levels of the 'traditional' Spanish. Because interpretation and understanding meanings are central in qualitative research, this might have resulted in loss of meaning and thus loss of validity of the qualitative study. Secondly, two healthcare workers from Prosalud accompanied me during all of my interviews. Although they only interfered whenever there was a language issue, their presence might have influenced the profundity of the interviews and honesty of the participants. Thirdly, the generality of the participants can be questionable because these people have received previous aid in healthcare with Prosalud's interference. However, I assume that these families and family members can be seen as representative for how families living with a mentally ill family member experience life, and cope with the mental disorder of their relatives because of the variability of the sample and the rather minor interference of Prosalud in mental healthcare.

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