Abstract

Despite evidence for the value of family-based interventions for mental disorders, there have been relatively few attempts to establish these in low-income settings. This chapter describes the development of a non-profit organisation, Cuenta Conmigo (CC), in Nicaragua which offers social support and education to families caring for relatives with psychotic disorders. In common with many low-income countries, Nicaragua has very limited mental mental health services and many families are living in conditions of poverty which can be exacerbated by the onset of mental illness. This chapter uses case examples drawn from the experience of the author in setting up CC to illustrate the potential benefits of the intervention for poor families in a rural town where there are few mental health services beyond brief psychiatric consultation and the provision of medication. The chapter also illustrates some of the challenges in ensuring the sustainability of CC, in particular securing long-term funding and the support of policy makers. The chapter concludes by arguing that community-based family interventions in mental health care can play an important role in enhancing recovery and social inclusion and can be implemented at low cost. However whilst non-governmental organisations such as CC are valuable in establishing such interventions, government commitment is vital to ensure their sustainability.

A family-based intervention for people with a psychotic disorder in Nicaragua

Rimke van der Geest

When researching the experiences of families with a psychotic family member in Matagalpa, a town in the central highlands of Nicaragua, I encountered most of my research participants by word of mouth. Talking about the topic, people often mentioned they knew someone who was 'loco' (crazy). One day, I was told about two brothers who talked to themselves. They lived in a small shabby house with their elderly mother. As usual, I decided to visit. A man with a beard sat grinning on the doorstep. He introduced himself to me as José[1] and started telling me about his brother Matías who was not doing well. I asked him whether I could introduce myself to him. José said I could but it was dangerous to enter the house because Matías might hit me. Than the mother appeared. 'Come inside', she said. She offered me a chair and we all sat down. Behind a small wall, I saw Matías lying on the floor; extremely skinny, dirty and wearing only ripped and worn pants. Around him were pieces of fabric, paper and plastic, some of them squashed together as a pillow. He ignored us and mumbled busily to the voices in his head. María apologised and said it was his own decision to lie on the floor.[2]

Introduction

The author of this chapter, who works as a psychiatric nurse in the Netherlands, has been visiting Nicaraguan families with a psychotic member over a period of ten years, first in the context of anthropological fieldwork, later through setting up and working with 'Cuenta Conmigo' (CC), a non-profit organisation that organises psycho-education and peer support for people with a psychotic disorder and their families in Matagalpa. She argues that by solely focusing on clinical management of individuals, there is a risk that valuable energy and money are wasted – patients continue to relapse or do not stabilize at all. Whilst antipsychotic drugs can be effective and cost effective for the treatment of

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[1] All names of patients and family members in this chapter are pseudonyms.

[2] The case material in this chapter is partly derived from Van der Geest (2009).

psychotic disorders, their benefits can be enhanced by psychosocial interventions, such as community-based family support and education (Patel et al., 2007: 991). By describing the working method of CC, an attempt is made to show that in a context of poverty and limited psychiatric care, it is possible to improve the lives of psychotic patients and their families with only a minimum of resources.

This chapter will describe the national mental health system in Nicaragua, before focusing on the town of Matagalpa. It considers what people do when their family member develops a psychotic disorder and what type of care is available. The author will then explain how the non-profit organisation CC has emerged and how it evolved into the organisation it is today. The chapter concludes with a discussion on the strengths, limitations and challenges of CC's approach.

The Mental Health System in Nicaragua

Nicaragua (population 6 million) is the second poorest country in Latin America after Haiti. Although poverty has declined in recent years, natural disasters and distortion of commodity prices in the international market has led to increased poverty in rural areas (World Bank, 2014, IFAD, 2014). The healthcare system of Nicaragua is divided into public and private care. Less than 1% of the national health budget is used for mental health care and 91% of this is used for the only psychiatric hospital in the country in the capital Managua. Psychiatric and/or psychological consultations are offered in 34 of the 177 public health centers. There are around 92 psychiatrists in the country. The majority (80%) work in the capital, mostly in private clinics. Since the 1990s specialists have opened private practices because of scarce job opportunities and low salaries in public mental health services and many psychiatrists emigrate within five years of completing their training. Only 2% of medical education is devoted to mental health, consequently medical doctors have little knowledge about psychotic disorders. Psychiatric nurses do not exist in Nicaragua. The nurses who work in the psychiatric hospital in Managua do not receive specialised education in psychiatry (Informe de Pais Republica de Nicaragua, 2005, Van der Geest, 2009, World Health Organization, 2011).

No exact data exist on the treatment gap for people with a psychotic disorder in Nicaragua. A review of epidemiological studies conducted between 1980-2004 estimated that in Latin America and the Caribbean over one-third do not receive care (Kohn et al., 2005). For those that do get help, the care is not very effective. Free medication in Nicaragua is limited to cheaper first generation antipsychotics like haloperidol, thioridazine and chlorpromazine. Despite their inclusion on the Ministry of Health’s basic medicines list, the supply is insufficient and availability varies from month to month. All this causes frequent discontinuation of and changes in treatment.

Given the unequal spread of psychiatrists in the country, for many Nicaraguans there is no psychiatrist nearby. To receive medication patients and family members have to travel to the nearest town. Crisis patients are referred to the psychiatric hospital in the capital Managua. The family has to pay for an ambulance or arrange their own transport. The hospital consists of four wards with 196 beds in total. The beds have no sheets and there is no possibility for patients to store private belongings. The average stay is over two months and there are 73 patients who have been in the hospital for more than 10 years. With one nurse and one assistant in charge of fifty patients there is little time for individual attention. Nurses are poorly motivated due to low wages and lack of specialised mental health training. Stories of violence and patients beating each other up are common (Informe de Pais Republica de Nicaragua, 2005, Van der Geest, 2009, World Health Organization, 2011).

An official mental health policy does not exist in Nicaragua. In 2005 a report on the current state of mental health services in Nicaragua was published by order of the Panamerican Health Organization / World Health Organization. It aimed to improve mental healthcare by creating a baseline for monitoring the progress in implementing new policies and developing community services. One of its recommendations was "to involve patients, families and other stakeholders in the promotion, prevention, treatment and rehabilitation of mental health." However in this respect, nothing much has happened. In 2009 there was an attempt to bring together policy makers and family members but the initiative stopped as there was no money to facilitate the meetings, or to pay the transport to Managua where the meetings were held. As in many other low-income countries, scarce financial resources and the low position of mental health on the political agenda are two of the barriers to improvement of mental health care in Nicaragua (Saraceno et al., 2007: 3).

Psychosis in Matagalpa: "It is better to leave him alone"

One of Nicaragua's regions is the coffee-dependent central region where the town of Matagalpa is situated. This region is home to 23 per cent of the Nicaraguan population, and 46 per cent of the country's poorest inhabitants (IFAD, 2014). Consequently having a psychotic family member in Matagalpa is often but one problem on top of several other difficulties:

The small house of María and her ill sons José and Matías, looked neglected; floor, walls and ceiling were full of cracks. The electricity had been cut off eight years ago because of unpaid bills. María only made a little bit of money from selling second-hand clothing in the street. The father of José and Matías passed away when the brothers were three months and three years old, respectively. He was shot in his taxi by a customer who refused to pay his fare. María had four more children with a second husband, three of whom died shortly after birth. The fourth child died six years ago at the age of twenty-four in a fight on a coffee plantation. Her second husband was a violent man, María does not want to talk about him.

When someone develops a psychotic disorder in Matagalpa, most people initially spend the little money they have on *curanderas* (natural healers) or *brujos* (witch-doctors). Such healers can be far away from the homes of those who consult them. Julio, the father of a psychotic young man in Matagalpa, travelled eight hours by bus to get to a recommended *curandera* who said that he and his son had to stay for a couple of months to be able to cure the disease. Julio decided not to stay. He could not afford to lose his job in Matagalpa as he had a family to feed. Sometimes psychotic symptoms are explained by beliefs in Satanic forces. Matagalpa has hundreds of churches, mostly evangelical, and some families decide to trust only God. They pray and invite faith healers to exorcise the evil spirits.

Eventually, some families find their way to the psychiatrist in Matagalpa. Dr Espinoza[3] started studying psychiatry after the revolution in the early eighties and has been working in Matagalpa ever since. He is available for consultations at the public clinic for an average of 45 minutes per day. Treatment consists of prescribing medication and/or referring patients to the psychiatric hospital in Managua. There is no time to explain about the origins of symptoms, the management of medication or possible side effects. Dr Espinoza does not keep medical records, he only writes down the patient's sex and age, asks which medication the patient is on and writes a prescription based on the information the family gives him. The patient is often left at home. This field note illustrates the brevity of such consultations:

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[3] This name is a pseudonym.

There is a queue of about thirty people in front of a door with the word 'psychiatry' written on it. When Dr Espinoza arrives, a nurse urges everyone to make room and stop pushing. It is 1.45 pm when the first patient is allowed to enter the consultation room. The patient tells the doctor that she cannot sleep at night. Her neighbour who accompanies her adds that she hears voices and sees things. The doctor asks whether she has been taking her medication. She says she has not been taking it for a while because the clinic had run out and it is too expensive to buy from the pharmacy. The next patient who comes in starts telling a story but unfortunately there is no time for it as the queue of waiting patients is long. The doctor hands her a prescription and she willingly leaves the room. Next is the mother of a woman who was found walking naked through the streets of Matagalpa a month ago. She is doing better after a recent stay at the psychiatric hospital in Managua. Dr Espinoza gives her a new prescription and calls the next patient in. He will see patient after patient until the last patient leaves at 2:30 pm. He has seen 15 patients in 45 minutes, an average of three minutes per consultation.

The conditions under which Dr Espinoza carries out his consultations are not favourable for the patients and their families. He refers to his work in the public clinic as charity work because his salary is so low. He works a couple of hours a day in a private clinic in addition to his job as a government official. In 2014 a consultation in the private clinic cost 25 US dollars, a price only the rich can afford, although poor people do get themselves into debt trying to get the best care for their loved one. The psychiatrist says his work is demanding with a lot of responsibility: "If a psychotic patient injures someone, people will blame me." The dosage of the antipsychotic drugs he prescribes is much higher than recommended in the guidelines. As a result, people get so many side effects that they often stop taking the medication.[4] In recent years second generation antipsychotic drugs have been introduced to the Nicaraguan market but these very expensive drugs can only be purchased from private pharmacies.

In 2009 a second psychiatrist was hired in Matagalpa to work some hours in the general hospital. Aside from the consultations in the hospital and the public clinic, there is no professional help available to monitor any medical treatment. The entire burden falls upon the family. They have to manage the patient's behaviour and make sure that he or she takes the medication. Besides the problem of side effects, the patient often stops taking pills because of lack of insight into the illness, typical of psychotic disorders. It makes families feel frustrated and hopeless. Sometimes family members themselves stop giving medication because they think treatment can be stopped once the psychotic symptoms have disappeared. Given the brevity of mental health consultations and lack of follow-up, it is unsurprising that they have this view. As a result patients relapse and problems start all over again.

According to María, Matías had not been taking any medication in ten years. She said he suffered from severe side effects whenever he took it. He had been admitted to the psychiatric hospital in Managua three times. María thought he was more rebellious than José, who had only been admitted once. Despite the admissions to the psychiatric hospital both sons remained ill. María said she could not afford to continue the search for a cure. In her opinion the only option left for her was praying to God; only He might be able to change the situation.

After years of struggling with a psychotic family member, families in Matagalpa often choose to "*dejarlo tranquilo*" (leave him in peace). They get to the point where they say: Let him do what he wants, do not argue with him, just accept that he cannot work or marry. The family of Camilo, a man that is – to this day – wandering the streets in Matagalpa,

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[4] Side effects of first generation antipsychotic drugs such as chlorpromazine are common and disabling and include tremor, restlessness, and muscle stiffness.

brought him to the psychiatric hospital seven times. According to his sister, Camilo had become ill after a doctor falsely informed him that he had HIV. He never recovered from this *susto* (shock) and has been talking to himself ever since.[5] Each time he was discharged from hospital, Camilo was less psychotic but then stopped taking medication and fell ill again. “Now, we gave up”, his sister explained. “This must be what he wants”.

Other families choose to lock up their psychotic family member for that person’s protection. The 25-year old psychotic girl Mirna used to run away from home and return without any clothes. Her parents locked her up to protect her from being raped. The girl’s psychiatric situation worsened dramatically due to the captivity but the family did not see other options. In 2006 Mirna escaped and jumped off a bridge. She survived but in 2007 she died of perforated intestines after swallowing metal nails she had pulled out the walls of her room.

Fear of stigmatization is another reason to 'hide' a psychotic family member from the outside world. Many Nicaraguans are convinced that all 'crazy' people are dangerous. If a psychotic person injures or murders someone, it will most likely reach the front page of the newspaper. This perpetuates the image of the mentally ill as violent and feeds a popular appetite for drama. Manuel, a psychotic young man in Matagalpa, injured eight people in 2007. His mother was invited by a national television show to tell the story. She was not happy about doing so, but she was poor and they paid her well.

From research to action

The focus of my 2004 Master’s thesis in anthropology was the impact of psychosis on families in Nicaragua. How do people deal with a psychotic family member in the context of poverty? Where do they search for help when information and professional care are not readily available? I did not disclose my background as a psychiatric nurse during the research, so as to encourage families to communicate openly about visits to traditional healers and the explanations they held for psychosis. One day however, I stepped out of my role as a researcher. It was the extreme suffering of an elderly couple that led me to move from research to action. The couple was struggling with their son, for whom they had spent years trying to find appropriate care to no avail. On top of that, they carried the burden of the tragic deaths of four of their other children. I told the father about the psychiatrist and he decided to visit. Dr Espinoza diagnosed the son with schizophrenia and prescribed medication. In the following months, the son got more stable and I gave the family information about the illness to help them understand what he was going through and that he was not the only person with this problem. This specific case ultimately led to the idea of founding a family-based intervention for people with a psychotic disorder in Matagalpa. In this town, where the burden of care came entirely down on families, it was hypothesized that providing family support and face-to-face psycho-education would facilitate more stability for the patient and therefore a better quality of life for the family as a whole.

The efficacy of family support in combination with education has been demonstrated in several studies worldwide. In high income countries it is shown that a combination of family support and education can lead to greater adherence to therapy, fewer relapses and fewer hospitalisations (Pitschel-Walz et al., 2001, Dixon et al., 2001). Research in Chile showed that caregiver burden[6] decreased significantly after taking part in a family intervention program, especially in

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[5] The explanations family members give for the change in their loved one are often formulated in a way that reduces social stigma. By naming external causes, like *susto* or hitting the head as a child, families are able to keep their dignity and social prestige (Van der Geest, 2009).

[6] The demands of caregiving include paying for psychiatric treatment, supervising the patient, dealing with the social stigma associated with mental illness, and coping with the emotional distress that the symptoms of the disorder may cause.

caregivers that had not previously received information about the illness (Gutiérez-Maldonado et al., 2007: 739-747). Also, there is increasing evidence that family-based care is more cost effective than institutional care (Saraceno et al., 2007: 4, Patel et al., 2007: 1000). Although there have been very few attempts to introduce family oriented care in low-income settings, including in Latin America, it seemed a feasible approach for Nicaragua where the mental health system is poorly developed and trained personnel is scarce. A study in a poor urban community in South Africa with limited access to mental health services, describes the positive outcome of an intervention with four multi-family groups (Asmal et al., 2014) and another study, carried out in one of the poorest areas of India, compared community based rehabilitation (CBR) with standard outpatient care and found that outcomes were markedly better in the CBR group (Chatterjee et al., 2003). A study in northern Ghana, where only a handful of community psychiatric nurses provide biomedical treatments, showed some evidence that the organisation of Mental Health Self Help Groups (SHGs) had positive effects on patients and caregivers. Social inclusion increased and outcomes of those who were ill improved because of more consistent treatment (Cohen et al., 2012: 6-7). The SHGs in northern Ghana were organised by BasicNeeds, the largest NGO working in this field. BasicNeeds works with governments to build a sustainable community based mental health care system in African and Asian countries, but to date does not work in Latin America. Their mission is to enable people with mental illness (or epilepsy) and their families to live and work successfully in their communities. The NGO has a broad based approach combining health, socio-economic and community orientated solutions with changes in policy, practice and resource allocation (BasicNeeds, 2015). By employing a similar approach and bringing together families I had met in the context of my research, it was hoped that a start could be made to change the present situation in Matagalpa.

The start-up of Cuenta Conmigo

Stedenband Tilburg-Matagalpa, a Dutch NGO working on issues of sustainable social development and located in Tilburg, the twin town of Matagalpa, was interested to help develop the idea of a family-based intervention for people with a psychotic disorder. Together with Comité Mano Vuelta, their partner organisation in Matagalpa, we prepared a plan in which the short-term goal was described as follows: uniting families and friends of people with a psychotic disorder and helping them set up a support group. A total of 5000 US dollars was raised by the NGO to cover initial set-up costs such as transport, office expenses, snacks and drinks for meetings and legal fees.

In 2005 I returned to Nicaragua and met the partner organisation. They provided me with a working space within their office and I started to look for a motivated family member to cooperate in the project. A suitable colleague was found with the help of the psychiatrist Dr Espinoza. He referred to Rosalba as a remarkable person since, unlike many other relatives attending his clinic, she always asked him questions about her son's illness. Her active interest was notable since in Nicaragua it is quite unusual to speak up to someone of high status. Rosalba liked the idea of forming a support group and offered to volunteer in the initial stages. Together we started to visit families in their homes. Most families felt honored by our visit. Many of them had not received visitors for a long time due to having a psychotic family member in the house. During visits Rosalba talked about her experiences as a mother and caregiver. Sharing the same problem and culture, she put the families at ease and encouraged them to talk about their experiences too. Sometimes Rosalba felt uncomfortable with a patient, since she was also influenced by stigmatizing ideas about the mentally ill being violent. Her fear disappeared over time as she learned more about the origins of psychotic symptoms and how these influence behaviour. At the beginning it was one of my main tasks to provide education on these topics. In subsequent years, Spanish-speaking Dutch psychiatric nurses were recruited to volunteer in Matagalpa to take on this role.

After a while we started to invite family members to share their experiences in a group. During these meetings there were feelings of recognition and relief but there appeared to be a great need for information too. We started to develop informative workshops about psychosis, medication and how to deal with difficult behaviour and problems with communication. Over time families started reporting that the atmosphere in their home was improving and that patients were doing better. Building on this progress, we started to organise activities in which both patients and relatives participated. These meetings were meant to reduce stigma and prejudice and to show families what their ill relative was still capable of. Patients and family members played games, painted, danced and became friends with each other.

Initially, María reacted with scepticism when she was invited to attend a meeting for family members of people with a psychotic disorder. She did not understand how this could help her, all she needed was money. When she was told that she could just attend and listen, she agreed to go. María discovered she was not the only mother with children that heard voices. She started enjoying life again. The visits from CC workers especially helped cheer up José. Years had gone by without anyone visiting their little house, and now he played the cheerful host whenever someone from CC came to visit. Every time he attended one of the family and patient meetings, he wore his shiny purple shirt. For the first time in six years José participated in activities outside his home.

To this day it is the leisure activities of CC that are appreciated the most. Rosalba and other family members say it reflects the misery families in Nicaragua live with where there is little possibility for poor people to do something fun outside the home.

Development of Cuenta Conmigo

To secure the project the NGO decided on paying a salary to Rosalba. As the day of my departure approached, I encouraged her and the other family members to take ownership of the project and make their own decisions. They decided on the name 'Cuenta Conmigo' meaning: 'You can count on me'. A more detailed project plan was made and CC's general goal became: “A better quality of life for patients suffering from psychotic disorders and their families”. The term psychotic disorder was deliberately chosen over schizophrenia to be able to include other psychotic illnesses, but also to minimise stigmatisation. The seven specific objectives to accomplish this goal were the following:

- Organizing a space where patients with psychotic disorders and their families can express their needs and experiences to learn from each other;
- Organizing psycho-educational gatherings so families can acquire skills to take care of their ill relative and of themselves;
- Providing face to face psycho-education and emotional support in the homes of patients and their families;
- Sensitising the community of Matagalpa and health authorities to the problems of patients with psychotic disorders and their families;
- Taking steps to work in collaboration with health professionals and other organisations;
- Lobbying the government for better care for patients with psychotic disorders.

The last two objectives were important. It was not CC's responsibility to *treat* patients. However, CC did want professionals to listen to them and involve them in treatment. Although there is evidence that peer workers working alongside professionals can be highly cost effective and reduce demands on other services (Repper, 2013: 13), the implementation can be difficult. Professionals are often attached to their methods and find it hard to accept the expertise of family members (Van Erp et al., 2006: 14). When the idea of the CC project was presented to Dr Espinoza, he did not respond positively and said that all Matagalpa needed was an inpatient clinic. Psychiatrists are often focused on clinical management of individuals rather than family-oriented care (Saraceno et al., 2007: 7). However, the case of Jonathan, a 23-year old young man from Matagalpa, shows the potential benefits of family-oriented care. Jonathan had been taken to the psychiatric hospital at least twice a year since the age of 15. He suffered manic-psychotic episodes in which he thought he was God and undressed himself in the street. His mother was convinced that the devil had taken hold of him when he was in this condition. Neighbours would tie Jonathan up and take him to the hospital. After a couple of weeks, sometimes months, Jonathan was stable again. However, he never continued taking the prescribed medication and soon relapsed. During depressive episodes, Jonathan's mother felt, ironically, relieved because her son would quietly stay in bed all day. However, Jonathan suffered tremendously during these episodes. Regular home visits by volunteer psychiatric nurses from the Netherlands and CC workers led to the mother understanding her son was ill and Jonathan accepting monthly injections. Jonathan is never entirely stable due to temporary unavailability of, or refusal to take, medication; however, hospitalisations have not been necessary ever since.

Local ownership versus foreign dependency

After one year the cohesion of CC had strengthened. Family members and patients called themselves one 'big family' and new ideas and activities had been invented. However, it had been a hard time for Rosalba. We had not foreseen that giving a poor woman a paid job would cause so much envy among neighbours and acquaintances. To become someone of status in Matagalpa, as in many poor rural communities in Nicaragua, can put the person in a vulnerable situation and invoke *envidia* (envy) and hostility from other members of the community. It took years before Rosalba received the respect she deserved. This is important to take into account when working through community workers in similar settings. Another challenge appeared as the Dutch government started to reduce its international aid budget as part of restructuring following the economic crisis of 2008. The NGO struggled to raise the necessary funds and over the next few years CC operated on a budget of around 5000 US dollars a year. Despite the difficulties, CC aimed to develop itself into a legally recognised NGO with its own office and meeting space. A psychologist was hired to conduct home visits so Rosalba could focus on the management of the organisation. A local committee of family members was set up and procedures to become registered as an official NGO were started. Furthermore, CC became a learning environment where Nicaraguan psychology and nursing students could gain practical work experience and Spanish-speaking Dutch psychiatric nurses, including myself, kept coming to Matagalpa to volunteer, bringing their own expertise and increasing their skills in working across cultures.

A psychiatric nurse that volunteered for CC searched for a solution to help María understand what her son Matías went through every day. While José was doing better, Matías continued to cause trouble for María. She did not understand why he refused to wear clean clothes and often yelled at him, calling him a pig, which aggravated Matías' restlessness. The nurse made her listen to a self-made recording of 'voices' played through a set of headphones. The voices talked over the top of each other and some of them gave instructions to the listener. María said the voices were making her 'crazy' and the nurse convinced her to visit the psychiatrist. Dr Espinoza advised to mix medication into Matías' drinks to reduce the intensity of his psychotic experiences.[7] *In the months that followed there were vast*

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[7] Covert administration of medication is common in low-income countries. In the absence of adequate health services health professionals and families feel they have no other viable alternative. The ethical aspects of this phenomenon relating to autonomy and consent have been discussed in several studies. Some argue that restoring the patient's capacity serves to promote their autonomy. Others argue that patients can be abused in the process (Srinivasan et al.,

improvements in his behaviour. He started greeting the visiting CC workers and sat down at the table with them when asked to. He also started looking in the mirror again, washing himself and wearing clean clothes. A CC worker accompanied Matías to the market to buy shoes, which required a lot of effort after twenty years of walking barefoot. The people in the neighbourhood noticed the changes in Matías' appearance and behaviour and started greeting him again. A complete recovery for Matías is very unlikely after having been psychotic for such a long time but it was touching to see the elderly María getting her son back.

In 2010 the Dutch NGO pulled out because of further government budget cuts and CC alone became responsible for raising all funds. The organisation was urged to look for funding themselves but this was complex as the family members who ran it lacked knowledge, written communication skills and suitable networks for fund raising. They applied for financial help from the local government but to no avail. The person in charge of mental health policy reported that mental health was not a priority of the Nicaraguan government and therefore there was no budget for such projects.

Nowadays most funds are raised by private networking and charitable fundraising in the Netherlands. The CC budget largely consists of overhead costs such as wages and rent, which public funds generally are not keen to subsidise. This donor condition is an obstacle to further development and the sustainability of the project. First of all it is unlikely that CC would continue to exist if work had to be done on a completely voluntary basis. Second, if CC is not able to rent a building, it will not be possible to create a space where people can meet. Eventually a Dutch family bought a house in Matagalpa to accommodate CC and a laundry service was set up to generate an income to cover CC's overheads. The washing-machines were also purchased by charitable donations from the Netherlands.

To strengthen its position and to increase opportunities to influence mental health policy in Nicaragua, CC participates in committees and with federations that are indirectly linked to the goals of CC. Workers from CC join meetings of the Municipality of Matagalpa, the local department of the Ministry of Health, and representations from national disability organisations, COMPED[8] and FECONORI.[9] However, compared to physical conditions, mental health care is never top of the agenda. In 2011 CC got involved in an exchange program of the Association for Training and Research for Mental Health (ACISAM[10]) in El Salvador and in 2014 this organisation started a four year project subsidised by the Inter-American Foundation (FIA[11]). The project aims to increase and strengthen a network of users and families in Central America. It wants to help them fulfil their potential to become empowered partners to improve mental health and be a model for reducing the global gap in mental health and combating the stigma of people with mental disabilities (ACISAM, 2014). CC is included as a member and in 2015 the Central American Network of service users and family members[12] had its first meeting. CC hopes that the forging of links with local and national organisations and membership of the international network will perpetuate its work into the future. However financial uncertainty remains. The laundry service, the small business that was meant to make CC more independent from external funding, is causing the family members a great deal of stress as the management is complicated and time consuming in addition to the other activities.

2002: 534-535, Teferra et al., 2013: 6).

[8] Comisión de Personas con Discapacidad (Commission for People with Disabilities)

[9] Federación de Asociaciónes de Personas con Discapacidad (Federation of People with Disabilities)

[10] Asociación de Capacitación e Investigación para la Salud Mental

[11] Fundación Interamericana

[12] Red Regional de Salud Mental Centroaméricana: Una red de grupos de usuarios y familiares (Central American Regional Network for Mental Health: A network of user groups and family members)

Cuenta Conmigo Today

CC staff currently include a coordinator, a psychologist, a bookkeeper, two laundry assistants and a local committee of volunteers consisting of four family members and one patient. CC works as a team. While each person is individually responsible for certain tasks, they often provide assistance to the others when needed. CC's goals and objectives are still more or less the same as ten years ago and meetings are still held on a weekly basis. Except for the leisure activities, the attendance of meetings is not high. This feature has also been reported by other countries in the Central America Network. Family members in Matagalpa say that they have the most benefit from home visits as they cannot always come to meetings because they have no one to care for their ill relative or other smaller children when they are away from home. Other family members have to work during weekends when meetings are held. In studies on support-group participation among lower socioeconomic caregivers other barriers to access are mentioned, such as transportation problems, hesitation over sharing feelings in the group or worry about getting along with other members (Biegel et al., 2004). Given the fact that CC's leisure activities are well attended, identifying more precisely the barriers at work here remains elusive. In surveys carried out to evaluate the activities, family members remain unclear about their motives for not joining group meetings but they consistently mention that CC has changed their lives in a positive way. Knowing that they are not alone, understanding of the illness and social acceptance are the most frequent benefits reported. There are about 90 families known to CC. On average, 53 are actively involved in the organisation. In 2014, 499 home visits were made. Families find out about CC through posters, public events, radio and local television, but mostly by word of mouth. The psychologist is often accompanied by a local psychology student, family member or foreign volunteer. They listen to the stories of the patients and family members and observe them in their home environment. Depending on each individual’s circumstances, they offer the family counseling, psycho-education and practical help. They write reports about the home visits. Once in a while the experiences of patients and family members are assessed through individual surveys using a questionnaire but structured evaluation of the CC program does not yet exist. There are no evaluation tools to monitor adherence to therapy, relapses or hospital admissions and there has never been a baseline measurement. This lack of formal evaluation makes it difficult to prove CC's effectiveness. Until today CC’s success is evident primarily through powerful personal stories[13]:

The question remained who was going to mix the medication into Matías’ coffee when María would die, because he would not take these by himself. María prayed every day, asking God to come and get her sons before her. Her prayers went unanswered and she passed away in 2009. José found her dead in bed early one morning. Several CC board members and family members attended her wake. People were glad that María could finally rest in peace but were also worried about her two sons. After María’s death, the neighbours raised money for a few repairs to the small house where José and Matías now lived by themselves. They also bought a bed for Matías. One of María’s sisters started to bring daily meals to her nephews and a neighbour became responsible for giving Matías his medication. José and Matías managed with the help of their aunt, neighbour and CC, although José’s mental health deteriorated a lot after his mother’s death. It became obvious that not he, but Matías had become the stronger of the two brothers. In 2011 José died of stomach problems and Matías remained alone in the small house. CC workers visit regularly and his aunt and neighbour are still looking after his food and medication. The situation is sad, but it would have been worse if Matías had become one of the many psychotic wanderers of Matagalpa. Matías’ metamorphosis had made a big impression on the neighbourhood. His neighbours are no longer afraid of him and even cherish him now that he is

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[13] This qualitative approach to evaluation has also been employed by BasicNeeds who collect first person narratives as evidence and use these to promote their work.

alone.

Discussion and Conclusion

This chapter describes the emergence of Cuenta Conmigo, a nonprofit organisation for individuals with a psychotic disorder and their families in Matagalpa, Nicaragua, which aims to improve quality of life through education and peer support by the means of home visits and group meetings. In Matagalpa it is seen that valuable money and energy are wasted when solely focusing on clinical management. If families do not get information on the illness symptoms, management of medication and possible side effects, patients continue to relapse or do not stabilize at all. The experiences of CC suggest the huge potential of family-based interventions to improve the quality of life of people with mental illness and their families in low-income settings. The positive outcome of CC's approach has so far only been derived from personal stories and surveys. These narrative accounts are important qualitative data but the organisation faces the challenge to put into practice a structured evaluation program to monitor its work and prove its success to policymakers.

The Lancet Global Mental Health Group (2007) calls for scaling up mental health services in low-income countries and developing community programs to improve mental health practice. However several barriers have to be overcome. In Nicaragua and many similar low-income settings, financial resources are scarce, mental health is a low priority on the public health agenda, and there is a lack of knowledge of mental illness among general health workers. The mental health system in Matagalpa is now limited to psychiatrists prescribing medication and/or referring patients to the only psychiatric hospital in Managua. CC hopes that the Nicaraguan goverment will invest in community-based care. As Murthy expresses it: “Developing countries have an unique opportunity to build mental health programmes on the strengths of families” (Murthy, 2003: 37). However he describes three conditions needed to support a family-based approach. Firstly, families require professional support to develop caring skills and access to crisis support and respite care, as well as emotional support. Secondly, families need financial support to replace income lost through caring responsibilities and to help them establish self-help groups. Finally family-based interventions will require significant shifts in attitudes and practices among policy makers and those working in mental health care to develop partnerships with families and make the experiences of the family an essential part of mental health programme and policy development (Murthy 2003).

As for CC, the organisation has been seeking cooperation with the local government but has encountered financial limitations and little official interest so far. The organisation has also been participating in local health committees and federations over the past ten years but it is hard to get mental health on the agenda. Although CC could play an important advocacy role in the battle for improving mental health practice, the organisation has very limited skills in this area. The Lancet Global Mental Health Group suggests that the World Bank, other development banks, donor agencies in high-income countries and philanthropists invest in strengthening the capacity of consumer organisations and engage them as equal partners (Global Mental Health Group, 2007: 94-95). However, negotiating on a macro level is not an easy task and CC workers do not speak English. The recent establishment of the Central American Network to help empower organisations like CC is grounds for cautious optimism. For the time being however, as with many small NGOs, CC continues to depend on private fund-raising activities in the Netherlands and the contribution of Dutch volunteers meaning that the future sustainability of the organisation remains uncertain. The experiences of CC suggest the potential value of family interventions in low-income settings. However more people could share in these benefits if mental health policy makers prioritise the needs of service users and family members, allocate funds for mental health, and reorganise health systems around community-based interventions.

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