

The lived experience of psychosis in Nicaragua: A qualitative examination of the views of service users.

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Abstract

Background: The experience of psychosis is individual and influenced by a complex intersection of identity, thought processes, perceptions and culture. Little is known about the lived experience of psychosis in Nicaragua.

Aim: To explore the subjective experience of psychosis in Nicaragua from the perspectives of service users.

Methods: Focus groups with 28 service users with experience of psychosis. A qualitative analysis using both inductive and deductive approaches was used to analyse these data.

Results: Participants mostly attributed the onset of psychosis to external factors such as physical or psychological trauma and highlighted the impact of long-term conflict in the area. Whilst medication was generally viewed positively where this was available participants foregrounded lay and community support networks and engagement in valued activities in their narratives about the management of psychosis. Religious and magical forces were salient in participants' accounts of causal pathways, wider Nicaraguan culture and management practices. Stigma, social exclusion and limited access to formal health services and psychological interventions in particular were the major barriers reported to recovery from psychosis.

Conclusion: Our findings point to the potential utility of culturally adapted psychological interventions in Nicaragua as well as the value of lay and community workforces in delivering such interventions.

Keywords: Psychosis; mental health; lived experience; Nicaragua; LMIC; qualitative study.

Introduction

The experiences and outcomes of mental distress are highly individualised. More unusual forms of distress, such as auditory and visual hallucinations, delusions, and losing touch with reality (which we will call here “psychosis” for lack of better terms) are influenced by a complex intersection between identity, thought processes, and perceptions (Jones & Shattell, 2016). These are shaped by the culture that a person lives in (Larøi et al., 2014; Luhrmann, Padmavati, Tharoor, & Osei, 2015). There has been much interest in studying the “psychosis continuum” within a cross-cultural context, which has demonstrated the heterogeneity of the experiences depending on culture (Ayazi et al., 2016; Wüsten et al., 2018; Wüsten & Lincoln, 2017).

Although psychotic experiences are common in Low and Middle Income Countries (LMICs), they are generally rated as less distressing and less pathological than in High Income Countries (HICs) (Wüsten et al., 2018). At the same time, individuals in LMICs are exposed to an elevated number of stressors (Lund et al., 2010), which may increase their vulnerability to psychosis (De Vylder et al., 2016). Much of the research in LMIC’s has focussed on large-scale epidemiological data, leading to interventions that are based on the biomedical disease model, which may not be culturally appropriate (Bracken, Giller, & Summerfield, 2016). Interventions that are not culturally adapted (Bracken et al., 2016) are unlikely to have direct relevance in LMIC settings, where daily struggles to survive poverty is one of the most pressing issues. Therefore, an important early stage of cultural adaptation of interventions is the development of an in-depth understanding of psychosis from the perspective of people with lived experience (White & Sashidharan, 2014).

This study focussed on exploring personal experiences of psychosis within a unique cultural context: Nicaragua. Nicaragua is a LMIC in Central America, with a population of 6.2 million. As well as richness in culture and natural resources, the country is plagued with political instability, historical scars of a civil war, natural disasters, violence, and poverty (Central Intelligence Agency, 2019). The population of Nicaragua has been exposed to multiple recent and historical traumas, all of which could potentially increase vulnerability to psychotic experiences (Mayo et al., 2017). Despite the high incidence of stressful life events (Vázquez, Panadero, & Rincón, 2007; 2010), mental health services in the country are minimal (Van Der Geest, 2011). Further, apart from a limited number of anthropological investigations into psychosis and community interventions in Nicaragua (Van Der Geest, 2011; 2017) and other Central American countries (Nickels, Arvaiza, & Valle, 2016), there is a dearth of research focussed on understanding the personal experiences of psychosis within this context. We aimed to gain an in-depth understanding of the lived experience of psychosis in Nicaragua from the perspectives of service users.

Materials and methods

Focus groups are a useful method of data collection when trying to understand multiple perspectives on the same topic and developing a shared understanding of social phenomena (Powell & Single, 1996). We conducted three focus groups with service users with lived experience of psychosis in the city of Matagalpa, the fourth largest city in Nicaragua. With a population of approximately 200,000, Matagalpa is the most commercially active outside of the capital Managua.

Participants and recruitment

People were eligible for the research if they were service users with lived experience of

psychosis. Participants were invited to take part through Cuenta Conmigo, an organisation established by families and patients with experience of psychosis, with the aim of providing a safe space to enable people to share experiences and support each other. Twenty-eight people with psychosis consented to take part in the study.

Participants were purposively sampled to include a balance of genders, ages and time since diagnosis (see Table 1). Recruitment stopped after completion of three focus groups (n 's 9, 9, and 10, respectively) in line with funding parameters.

Procedure

Focus groups were facilitated in Spanish by RB (clinical psychologist) in collaboration with SC (a psychology researcher). HB and ML were present to observe and support the digital audio-recording but did not participate in the group discussions. At the beginning of the session, RB read aloud the participant information sheet and participants had an opportunity to ask questions prior to giving written informed consent for participation and audio-recording of the session. Focus groups started by asking people about their experiences of living with psychosis in Nicaragua then moved to exploring attributions about the causes of psychosis, current management strategies and barriers to effective self-management (see Appendix 1). The focus group schedule was developed and refined amongst authors and then translated into Spanish by professional translation services, Matagalpatours.

Focus groups were undertaken in May 2019 and lasted between 60 and 90 minutes.

Groups were digitally recorded and transcribed verbatim before being translated into English for purposes of analysis by an experienced and independent translation

company based in Nicaragua, Matagalpatours, who have significant experience of

undertaking such work. Spanish versions of transcripts were checked and verified by the

Nicaraguan research team prior to translation. In order to compensate for transportation costs and potential losses of income, participants were given a \$10 payment for participation and lunch was provided after focus groups.

Data analysis

A qualitative content analysis using both inductive and deductive approaches was used to analyse these data (Hsieh & Shannon, 2005). ML, PE and HB first familiarised themselves with the data by reading and re-reading transcripts. ML and PE generated initial codes inductively within each transcript before meeting with HB to discuss the process of coding and to consider emerging interpretations in order to develop a more detailed understanding of the data. Further detail on authors' background and role can be found in Appendix 2.

Codes were then organised into deductive categories which reflected the particular topic domains discussed in the focus groups (e.g. causes of mental illness, current management practices, factors affecting recovery). In order to ensure these categories were fully developed, codes clustered under topic categories were further examined to identify the core salient features, which united the experiences of people with psychosis in Nicaragua within these domains (Braun & Clarke, 2018). To ensure no relevant data was missed any codes that fell out with these domain topics were then considered. Due to the strength of narratives relating to magical-religious forces in relation to the experience of psychosis in Nicaragua and the fact these codes spanned multiple domains within transcripts, it was decided that this would constitute a separate theme.

Data analysis was supported using memos developed by coders during the analysis process and by demographic data to contextualise the data. The final presentation of data was discussed with the wider study team to check analytical interpretations and

identify any potential discrepancies or inaccuracies. Data are presented using thick descriptions and presentation of sections of raw data to support interpretations and in an attempt to promote transparency of analysis.

Results

Four overarching themes were generated from the data. The first theme (i) the centrality of magical-religious forces was apparent in all focus group domains. The remaining three themes focussed on the three domains of discussions within focus groups: (ii) factors which precipitate the onset of psychosis (iii) current management practices (iv) (v) barriers to the management of psychosis.

The centrality of magical-religious forces in narratives about living with psychosis in Nicaragua

Approximately 80% of the Nicaraguan population identify as Christian (“Censo De Población”, 2005). In line with this the majority of participants in the current study self-identified as being religious, and felt their beliefs were an important way of coping with their symptoms. Religious activities participants engaged in included reading the Bible, praying, and attending church services. Several participants disclosed that prayer was often the first thing they turned to when in distress, even before seeking help from mental health services, friends, or family.

“I first pray to God, he is the doctor par excellence; and when I am stressed because of school and work I go to the church to seek for hope, my family and the church leaders.”

User 6, Group 1

A small number of participants felt magical-religious forces, particularly their God, could be potential cures for their symptoms. User 5 in Group 1 felt strongly that their

God had cured them, to the point where they had stopped taking their psychiatric medication altogether whilst User 7 in Group 1 reported a similar cessation of medication because of their belief in the curative power of religion but their condition had relapsed.

“I started to go to the church to pray, in the holy place, so God cured me. Now I don't take more medication”

User 5, Group 1

“I stopped taking the pills because I thought that God had cured me; but the convulsions came back.”

User 7, Group 1

Some participants reported that taking part in religious activities was a communal experience for them, often involving family or church workers. Due to their ubiquitous presence in Nicaragua, communal religious activities were an easy, accessible source of social interaction, allowing individuals to meet people in a structured and safe environment. As with User 4, Group 3 (quoted below), they may also represent a source of employment opportunities.

“The leaders of the church realized that I had a lot of knowledge about the Bible, so they proposed me to be a leader of the church...”

User 4, Group 3

Descriptions of witchcraft were prominent in participants' narratives particularly when they were referring to wider societal views of mental health. Participants described how people in Nicaragua often felt that psychotic symptoms were a sign of witchcraft or black magic. However, witchcraft was only explicitly identified by one participant in the current study as a direct cause of their symptoms. User 3 of Group 3 believed that their symptoms began after consuming cursed or poisoned food, contaminated via black

magic or witchcraft, as they began shaking and experienced chills. This quote also links with the theme “factors which precipitate the onset of psychosis”.

“There are bad people and witchcraft do exist and that was what happened to me. I did not believe in witchcraft before that, but now I do.”

User 3, Group 3

Factors which precipitate the onset of psychosis: the role of external factors as triggers of mental distress

Many participants disclosed some form of psychological or physical trauma to which they attributed the onset of their symptoms of mental illness. Psychological trauma typically included things such as domestic abuse, childhood neglect, homelessness, relationship breakdown or incidents during the Nicaraguan Revolution. For example, User 2 of Group 2 experienced long-term domestic abuse, living with and supporting a husband with severe cocaine and cannabis dependencies, as well as several children.

“I suffered from domestic violence and our relationship got worse every time. We lived together for 13 years. I came to Cuenta Conmigo to look for help for my husband who was addicted to cocaine and marijuana, he also used to drink a lot and he was womanizer...”

User 2, Group 2

The Nicaraguan Revolution lasted from 1961 to 1990, and permanently changed the face of the country (Hodges, 1986). The psychological impact of long-term violent conflict featured strongly in participants’ narratives about the causes of mental illness and participants coalesced in their attributions of mental illness being linked to traumatic experiences during the war. For example, User 9 of Group 1 went into a state of shock after her husband was violently murdered by Somoza guards, and described having suffered from her symptoms ever since.

“The Somoza guards kidnapped my husband and they cut his throat, I was working when I knew it and got in shock; so they took me to the hospital, since then I started to take pills and I still do.”

User 9, Group 1

Accounts of physical trauma also preceded participants' symptoms. For example, User 8 of Group 1 was involved in a bus crash and the age of six and described their symptoms (aggression, isolation, odd behaviours like burning money) starting shortly after. Others attributed the onset of mental illness to physical health conditions such as epilepsy.

“I have epilepsy since I was 2 years old. I hear voices and they blame me. I started to hear voices when I was 14 years old.”

User 1, Group 3

Current management practices: the foregrounding of lay and community support networks

Medication, support from lay and community support networks, relaxation/distraction techniques, and support from mental health services were the most common means of managing mental illness reported by participants.

A significant proportion of participants took one or more forms of psychiatric medication as a means of alleviating distress and narratives were generally positive about the effectiveness of medication. However, some participants struggled with the physical and psychological side-effects of their medication and received little input from health services to address these.

“My family, mother and sister, were of great support; I took a lot of pills that made me sick, I was almost paralyzed, that was a shock for me. I started to go to the church to pray, in the holy, so God cured me. Now I don't take more medication, it

is important not to depend on medication because medication causes other reactions”

User 5, Group 1

The positive contributions of community and lay support networks to the day-to-day management of mental illness were salient in participants’ accounts of the everyday experience of mental distress in Nicaragua. In particular, third sector organisations such as Cuenta Conmigo were viewed as a lifeline during times of crisis. This appeared to be because the organisation facilitated interaction with others who understood or who had direct experience of their condition and who had the time to support and get to know them.

The therapies I have gotten at Cuenta Conmigo have helped a lot.”

User 5, Group 1

Lay networks implicated by participants in the management of mental illness typically consisted of family (particularly mothers), friends, and neighbours. Support networks typically had two roles: as a means of social contact and as a way to leverage resources to help manage psychosis. For example, family and friends would often remind participants to take their medications as prescribed. Social networks also assisted in things such as financial support and taking participants to appointments when required.

“My family has always helped me a lot, my mother has always paid for my medication, and they treat me very well.”

User 5, Group 1

Distraction techniques (tasks that don’t directly work towards alleviating distress, but rather direct an individual’s attention away from the distress) were commonly cited, particularly household chores, reading and social interaction. Other useful techniques included exercise, listening to music, and watching television. Relaxation techniques

(tasks that directly work towards alleviating distress) were also discussed, albeit less frequently. Techniques such as breathing exercises, positive thinking, and a form of mindfulness were described. Overall, participants used distraction techniques far more frequently than relaxation techniques. Some of the participants described a combination of both distraction and relaxation exercises, for example:

“I try to do something; I listen to mantra music and relax in my bedroom; I do respiration exercises. I talk and encourage myself.”

User 4, Group 2

“I drink a glass of water and do respiration exercises.”

User 4, Group 3

“I pray and talk to my friends; I do respiration exercises and play the guitar; I like to sing. I like to be active and read.”

User 2, Group 1

Barriers to recovery from psychosis: limited access to care and social exclusion

Limited access to care

The most commonly cited barrier to the self-management of psychosis was access to health services and medication. There was a shared desire for psychological interventions to support self-management. Participants also described how medication was often unaffordable and even if they did have access to the funds to buy medication it was often not available in local pharmacies.

“Lack of pills; it is difficult to buy medication because it is very expensive.”

User 1, Group 1

Social exclusion

Societal stigma was also a significant barrier to managing mental illness and impacted negatively on social inclusion and individual recovery. Stigma often did not just come from family, friends, and neighbours, but also from a societal level with exclusion from opportunities for employment”. Some participants, such as User 1 of Group 3 had at one time had positive relationships with neighbours but since being diagnosed they had started to mock them for their condition, a fairly common story amongst participants. Several participants discussed feeling undervalued by society as a whole, often facing social exclusion including being denied employment opportunities. User 4 of Group 1 blamed the general population’s lack of understanding of psychological disorders as a primary drive of stigmatising attitudes and behaviours.

“There are too many social barriers, it is maybe because of ignorance and there are also rude people who call us crazy; all these offenses make us feel sad. It is true that we take medication but it doesn’t mean that we are not valuable; it was very difficult for me at the beginning to deal with the people’s offenses, but then I decided to ignore them.”

User 4, Group 1

Lay and community networks could be a valuable source of contribution to the work associated with managing mental health conditions where these are supportive and viewed positively. However, participants often described difficult relationships with family and friends which could detract from managing mental illness.

“My family does not love me, they do not give me medication. I have to remember myself to take the pills and sometimes I forget it; my son who is here with me is the only one who gives me medication...”

User 2, Group 1

“My family has been cruel with me, I have to go to the hospital alone when I feel sick, epilepsy scares me, and I cannot go out with my little son because I’m afraid of a car accident in the street.”

User 7, Group 1

Discussion

To our knowledge, this is the first study to explore the lived experience of psychosis amongst service users in Nicaragua. Although there has been much interest in researching the incidence and identification of psychosis in LMIC context (Burns, 2015), the epidemiological approach does not increase understanding of the beliefs and practises of local people around psychosis. Our qualitative findings give important insight into the lived experience of psychosis in Nicaragua and people's beliefs about the causes of their distress which are likely to be fundamentally important in the design of future culturally appropriate interventions.

Although the biomedical model of psychosis is evident in people's understandings of psychosis in LMIC's (Cosgrove et al., 2019), in a similar manner as in Western studies (Carter, Read, Pyle, & Morrison, 2018), service users in Nicaragua mostly felt that their psychosis had psychosocial and trauma-related origins. War experiences were stated as a common cause, as well as abusive relationships. These results support the findings of quantitative studies demonstrating the traumatic events such as war increase the odds of psychosis (Croft et al., 2019; Keraite et al., 2016) and lend support to assertions that psychosis is best understood as a normal reaction to traumatic experiences (Okkels, Trabjerg, Arendt, & Pedersen, 2017). Indeed, previous research in Latin American cultures has found that psychosis sufferers causal attributions are a complex mixture of biological, psychosocial, and magical-religious explanations (Caqueo-Urizar, Boyer, Baumstarck, & Gilman, 2015; Gómez-de-Regil, 2014). The explanatory models of our Nicaraguan participants supported the complexity and diversity of the experience of psychosis as identified in other LMICs.

Most participants highlighted the importance of medication, especially in the absence of psychological interventions but acknowledged that medication was hard to access in Nicaragua as in other LMICs, and could also lead to distressing side effects (Asher, Fekadu, & Hanlon, 2018). Participants instead foregrounded support from lay and community support networks and identified a range of self-management strategies, including engaging with valued activities and a range of relaxation/distraction techniques. Our findings point to the need for service providers to understand the activities that people perceive as important in relation to their mental health, the mechanisms through which these promote wellbeing and how they can best support engagement with valued activities in order to promote recovery from psychosis (Lal et al., 2013). In both LMIC and HIC settings, the voluntary sector is often considered best placed to promote engagement with valued activities, as these are generally considered more congruent with the ethos of third sector organisations than formal health services (Tew et al., 2012; Susanti et al., 2019). Data from the current study further highlighted the role of community organisations in the future development of Nicaraguan mental health care to ensure services meet the needs of people that access them.

Improving access to psychological therapies is likely to be fundamentally important in Nicaragua given participants shared desire for these types of interventions and their demonstrated effectiveness in other LMIC contexts, (Asher, Patel, & DeSilva, 2017). Indeed, increasing mental health interventions implemented by non-specialist community providers or lay workforces in LMIC contexts has been high in the agenda of several global organisations (Kohrt et al., 2018), and our Nicaraguan participants'

experiences highlight the importance of urgently increasing community provisions in this regard and integrating lay workforces into their delivery.

The salience of magical-religious forces in the experience of psychosis in Nicaragua featured prominently in all focus groups. Participants implicated religion and witchcraft in the context of causal beliefs, healing, and help, some of which appeared unique to Nicaraguan cultures. Not surprisingly, religious activities such as praying, reading the bible, and attending church were often discussed as efficient tools for managing distress. Religion was also important for participants in the current study because of its ubiquity in Nicaraguan culture and because it acted as a conduit to social interaction and community integration. Previous qualitative work has suggested that religion increases resilience via building communities, and in helping to construct identity (Virdee et al., 2016). Religion featured strongly in narratives about recovery for people in Nicaragua, highlighting the importance of incorporating religious and spiritual aspects into therapeutic interventions delivered in Nicaragua to ensure cultural acceptability and to optimise engagement (Irfan, Stone, Husain, & Phiri, 2016).

On the most part support from family, friends and communities was viewed positively and important sources of instrumental, informational and emotional support. It became obvious that the peer support group, Cuenta Conmigo, was fundamental in promoting wellbeing of the participants. Peer support has been recognised as having a great potential to aid recovery (Stant et al., 2011), although research evidence of its effectiveness is equivocal (see Gillard, 2019). Future studies will demonstrate whether peer-support will provide a cost-effective intervention model in the LMIC context (Puschner et al., 2019).

However, issues were identified in relation to some interpersonal relationships,

especially unsupportive behaviour from neighbours, family members, and wider society which appeared related to stigma. Stigma represents a significant barrier to recovery from psychosis in both LMIC and HIC settings but is comparatively underexplored in LMIC contexts (Corrigan, 2004; White, Ramachandran, & Kumar, 2017). This study supports these findings by highlighting the negative impact of stigma on recovery from psychosis for people in Nicaragua. Recent research suggests that community engagement events using arts-based activities which promote intergroup contact are a potentially useful way of reducing stigma towards people with mental illness in LMIC settings (Quinn, Shulman, Knifton & Byrne, 2011; Johnson, V & Stanley, J, 2007). Such activities may be useful in Nicaragua but should be locally contextualised prior to use in order to optimise implementation (Brooks et al., 2019).

Strengths and limitations

The study gains its strengths from the combination of in-depth qualitative analysis and focus group design. This study explored the views of service users only and future research should include the views of other key stakeholders such as health professionals, third sector organisations, traditional healers, spiritual/religious leaders and policy makers. All participants resided in the Matagalpa area of Nicaragua, self-selected for study inclusion and were members of Cuenta Conmigo. Data may therefore not reflect the views of service users in other areas of Nicaragua or those not involved with community organisations. Future research should consider in-depth interviews to explore some of the issues identified in the current manuscript in more depth.

Conclusion

In conclusion, our study demonstrates the fundamental importance of understanding lived experiences of psychosis within the cultural context of the individual. Our

participants had a rich personal understanding of the origins of their distress, often linking it to trauma-based experiences rather than the biomedical model. In addition, religion played an important part in management of symptoms, recovery, and providing social contacts. Our findings point to the potential utility of culturally adapted psychological interventions in Nicaragua as well as the value of lay and community workforces in delivering such interventions.

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Table 1: Demographic data

		% (n)
Gender	Male Female	39.3% (n=11) 60.7% (n=17)
Age	Mean Range	41.8 years 18-79 years
Role	Service user Carer and Service user Missing	75% (n=21) 14.3% (n=4) 10.7% (n=3)
Currently taking medication?	Yes	100% (n=28)
Time since diagnosis	Mean Range	11.9 years 6 months to 30 years
Education level	Primary school (1-6th grade) Secondary school (7th to 12th grade) University Missing	53.6% (n=15) 28.6% (n=8) 7.1% (n=2) 10.7% (n=3)
Currently working in paid employment?	Yes No	21.4% (n=6) 78.6% (n=22)
Numbers of current medication	Mean Range	2 1-4
Most common medication	Haloperidol Amitriptyline Lorazepam Carbamazepine Diazepam Valporic acid Chlorpromazine Olanzapine Risperidone Other Missing	8 6 6 4 3 3 1 1 1 7 4