Pathways to Care for Patients with a First Episode of Psychosis: A Multicentric and Multiethnic Study*

Vías de atención a pacientes con un primer episodio de psicosis: Un estudio multicéntrico y multiétnico

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ABSTRACT

The aim of this study is to describe the care pathways for patients with a recent onset of psychosis and to determine whether these routes are significantly affected by ethnicity and causal beliefs about this disorder. A total of 252 patients with schizophrenia in outpatient treatment (116 Aymara and 136 Non-Aymara) with a mean age of 35.6 years ($SD = 12.5$) from public mental health centers in Arica, Chile (33.6 %), Tacna, Peru (33.6 %) and La Paz, Bolivia (32.8 %) and their primary caregivers participated. They were interviewed regarding their help-seeking contacts using a semi-structured questionnaire. Out of the total patients, 64.7 % initially contacted a general practitioner for help, while only 14 % went to see a psychologist and 12 % sought a *Yatiri* (healers). The main factors associated with avoidance of a different route were the presence of a supportive family member or friend and the presence of a general practitioner. It is concluded that the main route of access to psychiatric services for patients with a recent onset of psychosis among Andean ethnic minorities is through a general practitioner, while a small portion of this population relies on community healers.

Keywords

duration of untreated psychosis; first psychotic episode; pathways to care; schizophrenia; causal beliefs; Latin America.

RESUMEN

El objetivo de este estudio fue describir las vías de atención para pacientes con una aparición reciente de psicosis y determinar si éstas se ven afectadas significativamente por el origen étnico y las creencias causales del trastorno. Participaron 252 pacientes con esquizofrenia en tratamiento ambulatorio (116 Aymara y 136 No Aymara) con un promedio de edad

de 35.6 años (*DE* = 12.5) de centros públicos de salud mental de Arica, Chile (33.6 %), Tacna, Perú (33.6 %) y La Paz, Bolivia (32.8 %) y el cuidador principal. Se entrevistó respecto a sus contactos de búsqueda de ayuda utilizando un cuestionario semiestructurado. El 64.7 % de los pacientes contactó inicialmente a un médico general para solicitar ayuda, mientras que sólo el 14 % consultó a un psicólogo y el 12 % se refirió a *Yatiri* (curanderos). Los principales factores asociados al hecho de evitar una vía distinta fueron la presencia de un familiar o amigo de apoyo y la presencia de un médico general. Se concluye que la principal vía de acceso a los servicios psiquiátricos para pacientes con una reciente aparición de psicosis entre las minorías étnicas andinas es a través de un médico general, mientras que una pequeña parte de esta población depende de los curanderos de la comunidad.

Palabras clave
duración de la psicosis no tratada; primer episodio psicótico; vías de atención; Esquizofrenia; creencias causales; América Latina.

A growing body of research on schizophrenia and related psychoses has focused on the first psychotic episode (Marshall & Rathbone, 2006). Schizophrenia's early detection and management through specialist services are among the most important developments in mental healthcare services. Previous findings have suggested that schizophrenia outcomes are determined by the duration of untreated psychosis (DUP), which is understood as the duration of definite positive symptoms or the onset of illness prior to the patients first time seeking for treatment (MacBeth & Gumley, 2008). This delay between the onset of psychotic symptoms and the start of treatment has been associated with poor clinical and functional outcomes in different countries, including England, Norway, Australia, Germany, Canada, and Chile (Anderson et al., 2015; González-Valderrama et al., 2015; Larsen et al., 2000; Marshall et al., 2005; Marshall & Rathbone, 2011; Norman et al., 2005; Perkins et al., 2005).

To improve the care system for subjects experiencing a first episode of psychosis, it is essential to gain knowledge about the help-seeking behavior of patients and caregivers and this behavior may be influenced by ethnic group membership. A patient's ethnic context may influence their beliefs about the cause of mental disorders and the most appropriate course of action (Anderson et al., 2015; McCabe & Priebe, 2004; Sheikh & Furnham, 2000).

Studies have examined this phenomenon since the 1990s. Gater & Goldberg (1991) examined pathways related to pre-admission among a diagnostically heterogeneous sample including 250 patients with psychosis who were admitted for the first time in South Manchester. Out of these patients, two thirds were admitted to psychiatric hospitals by general practitioners. Similarly, a study by the Southern Community Psychiatric Service of Verona found the most common pathway for patients experiencing a first episode of psychosis to receive mental health services was through the recommendation of a general practitioner (Amaddeo et al., 2001). Additionally, Garety & Rigg (2001) investigated patients in London who had experienced a first episode of psychosis and reported that half of them were taken to a hospital by the police. Finally, another study found that half of the patients admitted to a hospital due to a first episode of schizophrenia contacted a general practitioner prior to their admission, whereas one third went to see a mental health professional (Lincoln et al., 1998). A clear understanding of patients' avenues to care after a first episode of psychosis is crucial, since patients' initial experiences and interactions can have long-lasting impacts on whether they continue or not to seek help and adhere to treatment.

Some researchers have suggested that both ethnicity and low-quality social networks influence patients' care pathways and DUP. Specifically, ethnicity may influence care pathways by influencing patients' explanatory models of illness, social connections, and help-seeking behavior (Norman, 2014). For example, Anderson et al. (2014) reviewed variations in pathways to care based on ethnicity during patients' first episodes of psychosis and found that Black patients were significantly less likely to involve a general practitioner and more likely to experience police contact as compared to White patients.

Currently, it is recognized that patients from ethnic-minority groups defined as "psychological communities" whose members share a persistent sense of common interest and identity based on some combination of shared historical experience

and cultural values —beliefs, language, way of living, or a common homeland (Harff & Gurr, 2004, p. 3)— have worse access to the mental health system than patients from ethnicities generally understood as belonging to a dominant group (Ramos et al., 2015). Reasons for these unequal experiences include multiple social disadvantages, such as living in urban settings; low socioeconomic status; access to only low-resource services; unemployment; and chronic experiences of exclusion, racism, and interpersonal and social discrimination (Halvorsrud et al., 2018; Mann et al., 2014; National Coordinating Centre NHS Service Delivery Organ R & D. [NCCSDO], 2005; Nazroo, 2003; Paradies et al., 2014).

In fact, some ethnic groups often enter the system through the compulsory admission by the police with limited participation by their treating physician (Winkler et al., 2016). In contrast, receiving emergency care services to treat acute events of schizophrenia is common, which is advantageous for the establishment of a follow-up system for patients with schizophrenia who, otherwise, would not receive attention (Marco & Vaughan, 2005). However, ethnic minorities experience compulsory admissions at an excessive rate, which can only fractionally be explained by higher rates of psychosis or later interventions to address mental health issues, leading to an overuse of emergency services as compared to other amenities (Mann et al., 2014). For example, Harrison et al. (1989) found that some ethnic minorities (i.e., the Afro-Caribbean population) wait longer to seek help after a first episode of psychosis as compared to patients from the general population. Furthermore, Pipe et al. (1991) suggested that ethnic minorities, such as Afro-Caribbean youths, were perceived as more threatening due to ethnic stereotypes and had a higher risk of both mandatory admissions and reduced use of mental health services. More recent studies concerning Black patients found persistently negative patterns of inequalities in pathways to psychiatric care as compared to other ethnic groups (Halvorsrud et al., 2018). However, the determinants of pathways to care related to ethnicity and other variables that

may affect individuals who have experienced a first episode of psychosis remain to be defined (Anderson et al., 2014).

Another consideration is that greater difficulties in accessing psychiatric treatment exist in low- and middle-income countries due to lack of infrastructure, human resources, and adequate treatment options, leading a significant number of patients and families to seek help from traditional and religious healers (Burns & Tomita, 2015; Davy et al., 2010; Kohn et al., 2004; Mesfin et al., 2009; Sorsdahl et al., 2009).

In Singapore, a study showed that a quarter of multi-ethnic patients approached a traditional healer prior consulting a psychiatrist (Chong et al., 2005). Also in Singapore, the results of a recent study found that individuals of Malay and Indian ethnicities were more likely to make first contact with non-formal sources than a primary medical care provider (Jeyagurunathan et al., 2018). A study in India revealed that approximately 68.5 % of patients sought healers as their first source of help (Lahariya et al., 2010). Finally, the findings by Burns and Tomita (Burns & Tomita, 2015) in Africa showed that 17.0% of people with mental disorders firstly sought help from traditional healers and 26.2% from religious healers.

To the best of our knowledge, little to no data exists from Latin-American countries regarding the pathways to care for patients with a first episode of psychosis. Additionally, given that Chilean psychiatric care is predominantly provided by psychiatrists and psychologists who are accessible by patients without the mediation of a general practitioner, the findings above from other countries are not transferable and may not reflect eh Chilean situation.

The objective of this study is both to describe patient behavior in pursuing pathways to psychiatric care when experiencing a first episode of psychosis and to determine whether these behaviors are significantly affected by ethnicity and causal beliefs concerning the disorder.

Methods

Sampling procedures

The sample herein consisted of both patients with schizophrenia who were receiving mental health treatment and their caregivers. In total, the sample included 252 patients diagnosed with schizophrenia by a psychiatrist using the ICD-10 criteria and their caregivers (33.6 % from Chile, 33.6 % from Peru, and 32.8 % from Bolivia) (World Health Organization [WHO], 1992). Caregivers were invited to participate in the study when they accompanied their family member with schizophrenia to outpatient mental health treatments. Furthermore, caregivers had similar sociodemographic characteristics, including schooling and job training, to those of the patients.

Similarly, the mental health centers that participated in this study had similar characteristics in terms of size, availability of treatments and professionals, and treatment costs. In contrast, some differences were observed in both the policies implemented and the level of investment in mental health, which reflects the differing developmental levels of the countries examined. According to information provided by the Pan-American Health Organization in its Mental Health System Report for Latin America and the Caribbean, Chile allocates 2.1 % of the health budget to mental health. While the majority of these funds are used for ambulatory treatment, where access to essential psychotropic drugs is free and universal, only 33 % is invested in psychiatric hospitals. In contrast, Bolivia's budget is only 0.2 % of its total health expenditure for mental health. The difference in the allocation of resources between hospitals and outpatient centers is not known, while free access to essential psychotropic medications benefits only 1 % of the population. In Peru, investment in mental health amounts to 3 % of the total health budget; specifically, free access to essential antipsychotics is not provided, and the majority of mental health expenditure (98 %) is allocated

to psychiatric hospitals (Pan American Health Organization [PAHO], 2013).

Procedures

This study was approved by both the Ethics Committee of the University of Tarapacá and the National Health Service of Chile. Prior to beginning the investigation, informed consent was requested and obtained from all participants who were thoroughly explained the objectives of the study. No reward was offered for participating in the study.

Two external psychologists, supervised by the main investigator, evaluated both patients and caregivers. The main assessment lasted 20–30 minutes and included a structured interview to collect demographic and clinical data, the application of a severity scale, and to ask the following question to the caregiver: "When your family member reported the first signs of the disorder, who did he/she consult first?".

Instruments

The Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987) was used in this study. It consists of 30 items that evaluate the schizophrenic syndrome, scored according to a Likert scale with seven degrees of severity. Specifically, level 1 on this scale indicates the absence of symptoms, whereas level 7 indicates the presence of extremely severe symptoms. Additionally, this instrument comprises three subscales associated with different types of symptoms, namely, positive, negative and general psychopathology. The PANSS was translated and validated by Peralta & Cuesta (1994) in Spain and by Fresán et al. (2005) in Mexico. This instrument was found to have good inter-observer and construct validity, high internal consistency (Cronbach's alphas of 0.73, 0.83, and 0.87 for the positive, negative, and general psychopathology scales, respectively) and adequate test-retest validity (intraclass correlation coefficient of ~0.80 for the three subscales).

Survey for Relatives and Patients Regarding Causes of Schizophrenia (Caqueo-Urízar et al., 2015). This instrument was designed to measure patients' beliefs regarding the possible causes of Schizophrenia. It provides 16 items that are recorded on a Likert scale in which: 0 = no cause; 1 = possible cause; and 2 = cause. The items were divided into three domains with a score calculated for each: *Biological causes, Psychosocial* causes and *Magical-religious causes.* This subscale was developed using information gained from key informant interviews (anthropologists, an intercultural Aymara consultant) and from the literature review. For the current sample, Cronbach's alpha, a measure of internal consistency reliability, was 0.80 for the *magical-religious* domain, 0.73 for *psychosocial* domain, and 0.58 for the *biological* domain in the patients' survey and was 0.81 for the *magical-religious* domain, 0.63 for *psychosocial* domain, and 0.49 for the *biological* domain in the caregivers' survey. Scores for the three causal belief domains were standardized to a mean of 0 and a standard deviation of 1 (Caqueo-Urízar et al., 2015).

Statistical methods

All statistical analyses were performed using SPSS 22. Based on the sample distribution, group comparisons were calculated using either t-tests or the Mann-Whitney-U test and Chi-squared tests. Correlations were calculated using Spearman's correlation. Finally, an analysis of variance was conducted regarding country, ethnic group, and timing of patients' first visit.

Results

A total of 252 caregivers and patients participated in the present study. Most of the caregivers were women, without a partner and with a poor schooling. In contrast, patients were primarily middle-aged, unemployed, and Aymara men (46.2%). The severity of symptoms was generally moderate, with an average PANSS score of 71.3 (SD = 28.2). Participant details are presented in Table 1.

Table 1
Participant characteristics (N = 252)

Primary Caregivers	M (SD)	Patients	M (SD)
Gender (%)		Gender (%)	
Male	32.3	Male	66.4
Female	67.7	Female	33.6
Age	54.7 (14.4)	Age	35.6 (12.5)
Relationship		Aymara (%)	
Mother	45.5	Yes	46.2
Other	54.5	No	53.8
Aymara (%)		Age at onset of disorder	20.9 (6.5)
Yes	51.4		
No	48.6	Duration of untreated psychosis (DUP) (years)	2.7 (4.9)
Marital status (%)			
Married	47.8	Average number of hospitalizations (past 3 years)	1.3 (1.5)
Single	52.2		
Educational level ≥ 12 years (%)	26.1		
Religion (%)		Type of treatment (%)	
Catholic	64.2	Only Pharmacological	87.7
Christian (unspecified)	10.0	Integrated	12.3
Evangelical	12.7	Severity of the disorder (total PANSS score*)	71.3 (28)
Jehovah's Witness	3.1		
Other	10		
Religious involvement (%)			
Low	48.6		
High	51.4		
Monthly family income** (US Dollars)	417.6 (429.4)		
Daily hours spent with the ill relative			
< 6 h	44.4		
≥ 6 h	55.6		

Note. SD: Standard deviation; PANSS: Positive and Negative Syndrome Scale for Schizophrenia. *PANSS total score 58 = Mildly ill, PANSS total score 75 = Moderately ill, PANSS total score 95 = Markedly ill, and PANSS total score 116 = Severely ill. **The monthly family income accounts for the economic contribution of all family members.

Data concerning which kind of provider patients first visited following the experience of the initial signs of schizophrenia are displayed in Table 2.

Table 2
Treatment during the first instance of care

Treatment performer	Frequency	Valid percentage
General Practitioner	163	64.7
Psychologist	37	14.7
Yatiri	31	12.3
Other	21	8.3
Total	252	100

As shown in Table 2, most of the patients contacted a general practitioner. The differences are highly significant regarding general practitioners as patients' choice (Chi-squared = 213.7; p = 0.000).

Additionally, statistical analyses of the variables were performed using appropriate tests based on the type of variable. All variables were non-significant. A 3 x 2 x 2 analysis of variance was, therefore, performed with country x ethnic group x first visit.

The results displayed in Tables 3 and 4 show that patients' psychosocial beliefs differed significantly between countries, with Bolivia's scores being the lowest and Peru's the highest.

In all three countries, there were significant differences in the biological beliefs of caregivers, finding in Bolivia the lowest and in Peru the highest. In Peru, caregivers scored higher in terms of psychosocial beliefs than did caregivers in Chile and Bolivia.

By analyzing DUP according to ethnicity, country of origin, and first professional visited and with all interactions between the variables, significant differences were obtained only for country of origin (F = 4.77, p = 0.009). DUP was significantly lower in Peru than in Bolivia. Chile was not significantly different from the other two countries.

Table 3
3 x 2 x 2 Variance analysis: Country x Ethnic group x First visit

Variable		Country	1st Visit	Ethnic group	Country x 1st Visit	Country x Ethnic group	1st Visit x Ethnic group	Country x 1st Visit x Ethnic group
Caregivers'	F	22.802	0.050	10.379	0.359	0.776	1.743	0.158
biological beliefs	p	**< 0.001**	0.823	**0.001**	0.699	0.462	0.188	0.854
Caregivers'	F	16.272	0.177	0.837	1.480	2.593	0.440	1.242
psychosocial beliefs	p	**< 0.001**	0.674	0.361	0.230	0.077	0.508	0.291
Caregivers' magical-	F	12.012	0.451	2.506	3.719	1.383	1.077	1.557
religious beliefs	p	**< 0.001**	0.503	0.115	**0.025**	0.253	0.300	0.213
Patients' biological	F	14.470	2.198	0.003	1.647	0.350	0.475	0.037
beliefs	p	**< 0.001**	0.140	0.959	0.195	0.705	0.491	0.964
Patients'	F	17.160	3.724	0.023	0.224	0.029	0.288	0.487
psychosocial beliefs	p	**< 0.001**	0.055	0.879	0.800	0.972	0.592	0.615
Patients' magical-	F	3.709	0.970	0.033	8.557	1.971	0.132	5.399
religious beliefs	p	**< 0.001**	0.326	0.856	**< 0.001**	0.142	0.717	0.005
Total PANSS	F	5.263	0.290	1.348	1.067	0.567	1.344	0.299
	p	**< 0.001**	0.591	0.247	0.346	0.568	0.248	0.742
DUP	F	4.765	0.000	2.325	0.102	0.459	0.334	2.297
	p	**< 0.001**	0.992	0.129	0.903	0.632	0.564	0.103

Note. PANSS: Positive and Negative Syndrome Scale for Schizophrenia; DUP: Duration of untreated psychosis (years). **Bold** remarks *p value* significant at 0.05 or 0.005.

Table 4
Averages of variable correlations that indicated significance (country of origin)

Variable	Peru	Bolivia	Chile
Patients' biological beliefs	0.676	-0.531	-0.153
Patients' psychosocial beliefs Patients	0.717	-0.454	-0.267
Patients' magical-religious beliefs Patients	0.554	-0.320	-0.227
Caregivers' biological beliefs Caregivers	0.710	-0.574	-0.157
Caregivers' psychosocial beliefs Caregivers	0.613	-0.332	-0.296
Caregivers' magical-religious beliefs	0.669	-0.365	-0.298
Total PANSS score	71.42	78.53	64.88
DUP	1.39	3.84	2.82

Note. Beliefs scores are presented in Z scores.

Table 5 shows that in Chile, the magical-religious beliefs of Aymara patients who first visited a *yatiri* were higher than those of non-Aymara patients or those who visited health professionals.

In Peru, the average magical-religious belief scores of caregivers who consult healthcare professionals are higher than among those who consult *yatiri*. In Chile, the average magical-religious belief scores are lower among caregivers who consult health professionals than those who consult *yatiri*.

Table 5
Mean Magical-religious beliefs scores by Country
First visit

Country	First visit	Patients		Caregivers	
		M	*SD*	*M*	*SD*
Peru	Healthcare professionals	0.717	0.105	0.709	0.107
	Yatiri	0.372	0.287	−0.368	0.292
Bolivia	Healthcare professionals	−0.370	0.115	−0.338	0.117
	Yatiri	−0.398	0.192	−0.323	0.196
Chile	Healthcare professionals	−0.384	0.110	−0.326	0.112
	Yatiri	0.296	0.234	0.276	0.239

Discussion

This study sought to both describe the behavior related to the healthcare pathways of patients who have experienced a first episode of psychosis and determine whether these behaviors are significantly affected by ethnicity and causal beliefs concerning the disorder.

Our results indicated that 64.7% of patients in the study went to see a general practitioner at first, while 14% sought help from a psychologist and 12% from traditional healers (*yatiri*). These results are consistent with those from Gater & Goldberg (1991), Amaddeo et al. (2001) and Lincoln et al. (1998) who reported that 76%, 50%, and 40% of their samples, respectively, contacted a general practitioner at first. Nevertheless, contact with a traditional healer was more evident in our sample as compared to that of other studies, but it occurred at a lower rate than that reported in Africa, Singapore, and India (Burns, & Tomita, 2015; Chong et al., 2005; Lahariya et al., 2010).

Furthermore, our results on help-seeking behavior suggested that the time interval between patients' first prodromal symptoms and their first help-seeking contact was approximately 2.7 years (*SD* = 4.9), which is longer than that found in another study that reported an average delay of approximately one year before receiving psychiatric treatments (Penttilä et al., 2014). In this study, the average delay of 140 weeks was positively correlated with negative long-term results. Patients experienced

an average of 1.3 hospitalizations in the past three years and had average PANSS scores of 71 points. Furthermore, negative symptoms that are difficult to recognize and treat promptly were predominantly observed in this sample. This finding suggests that information campaigns about the negative and nonspecific symptoms of schizophrenia are necessary and quite important.

Although a difference between patients with either long or short DUPs in terms of their healthcare pathways was not found prior to psychiatric admission, patients with a longer DUP sought help after a longer period of time. However, differences in the time interval between the first healthcare contact and admission were not observed. Also, in this study, DUP was not associated with causal beliefs as was expected. Therefore, a longer DUP does not necessarily relate to the delayed reaction of patients contacts; rather, it is more likely the result of a belated visit. Melle et al. (2004) found that factors such as poor support networks to be associated with quite longer DUP and delayed help-seeking.

Notably, among the 252 patients, only 31 initially contacted a traditional healer (*yatiri*). Therefore, it appears that the role of *yatiri* does not involve the early recognition of psychosis in the Andean population of Chile, Peru, and Bolivia. Furthermore, given that in the past decade, public health services have made a concerted effort to avoid discrimination against indigenous populations and to achieve greater levels of contact with indigenous populations through health centers, patients' contact with traditional faith healers may have been impacted (Ministerio de Salud de Chile [MINSAL], 2006; Ministerio de Salud de Perú [MINSA], 2004).

In this study, as in research conducted in Africa, regional differences were observed (Burns, & Tomita, 2015). In this study, Bolivia had a higher percentage of patients who first contacted a traditional healer. Similarly, it has been observed in Canada that nonnative youth living in rural regions sometimes seek help from informal and traditional supporters, such as counsellors and traditional healers. Difficulties with acculturation and identity can increase the

impact of stigma and can impair patients' use of mental health services (Archie et al., 2008; Boydell et al., 2006; Cauce et al., 2002; Duran et al., 2005).

Our study has some limitations. Given that only patients who received treatment at the mental health centers could be interviewed, potential bias may have existed in the sample selection. Additionally, data concerning both the number and the symptoms of those patients who either were not admitted to mental health centers or did not contact a mental health professional were not available. Future research should include more specific fieldwork in the Andes region involving those patients who are outside of the mental health system.

Despite the abovementioned limitations, this study provides initial insights into the help-seeking behaviors of patients with a first episode of psychosis that considers their ethnicity and the availability of services in this Latin-American context. Our findings may reflect some changes in Aymara cultural values, including a transformation in conceptions of mental disorders, which opposes the previous conceptions involving magical-religious forces (Caqueo-Urízar et al., 2015) as well as the novel reliance on doctors rather than traditional healers (i.e., the *yatiri*).

These changes likely reflect the large-scale migration of Aymara families from rural to urbanized areas, which is associated with the increased acceptance of the biomedical model of mental disorders and the assimilation of Western culture (Gundermann, 2000; Gundermann et al., 2007).

Conclusions

Greater attention should be devoted to factors that determine the pathways through which people who have experienced a first episode of psychosis initially contact the healthcare system. In particular, more studies on the specific needs of minority ethnic groups are required to develop interventions aimed at preventing secondary damage that may result from either

extensive DUPs or negative first experiences with psychiatric care services.

Furthermore, general practitioners and psychologists should be highly involved in disorder detection, the adequate referral of people who have experienced a first episode of psychosis, and the planning of care programs for these patients. Finally, the healthcare system should devote more attention to those patients lacking a social-support network to minimize the additional risk of delayed treatment and the associated adverse outcomes.

Acknowledgements

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Notes

* Research article.