

PATHWAYS TO PSYCHIATRIC CARE IN CHILDREN AND ADOLESCENTS WITH FIRST EPISODE PSYCHOSIS

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Abstract: An understanding of the probable path of mental health services is central in evaluating the existing mental health services. "Pathways to care" is referred to in sequence of contacts with individuals and organizations prompted by the distressed person's efforts. Studies across the world on first episode psychosis have consistently found a treatment gap of 1-2 years (or average) between the onset of psychotic symptoms and the start of treatment.

To explore the pathways to psychiatric care in relation to Children and Adolescents diagnosed with First Episode Psychosis.

This study is cross sectional, hospital based, time bound study from June to December, 2012. Purposive sampling technique is used to select the samples of the study. This study is conducted at Out-Patient Department of Centre for Child and Adolescent Psychiatry (CCAP) of Central Institute of Psychiatry (CIP), Kanke, Ranchi. Respondents of present study were the primary caregivers of the patients. The tools were assessed on Socio Demographic and Clinical Data Sheet, Analysis of the Delay in Accessing Psychiatric Treatment (ADAPT) and Brief Psychiatric Rating Scale for Children (BPRS-C)

Findings indicate that mean duration of untreated psychosis was 155.5 ± 304.5 days and the mean age of the patients was 14.8 ± 2.0 years. Majority of children and adolescents with first episode psychosis was diagnosed Mania with psychotic symptoms (34.7%). The mean duration taken to access psychiatric services after the identification of problem was 43.5 ± 101.0 days. Most common source of referral to psychiatric care was from relatives (73.6%). The most common first modality of treatment was by faith healers (61.1%)

Introduction: It is essential to know about the pathways to psychiatric care because it will help us in a better planning of psychiatric care services. The early identification and thereby management is very important in patients suffering from psychiatric illness. Hence, any cause leading to delay should be identified at the earliest. An interpretation of the probable path of mental health services is central in evaluating the existing mental health services. "Pathways to care" is referred to in sequence of contacts with individuals, organizations or institutions prompted by the distressed person's efforts to seek help, and assistance is provided in response of those efforts (Rogler & Cortes, 1993). In other words pathways to care is defined as the series of steps or contacts the patient or patient's family through psychiatric, medical or other services (e.g., Faith healers, Ayurvedic and Homeopathic) before their entry to psychiatric care. Variation has been found in the literature in this regard as it varies from one country to another and from one culture to another (Kumari, et al. 2004).

Three patterns of psychiatric care pathways have been identified in research evidence. The first pattern is dominated by the role of primary care physicians who refer them to mental health professionals when need arises and the second pattern where patients can visit any specialist of their choice including mental health professionals. The third pattern is reported in developing countries like India where faith healers play an important role in the pathway to

care (Abiodun, 1995; Naqvi, Hussain, Zaman, & Islam, 2009)

Early onset of psychosis is very rare in pre-pubertal children (Burd & Kerbeshian, 1987; Gillberg & Steffenburg, 1987) and there is limited epidemiological knowledge on this early onset disorder. From the information available it has been estimated that the prevalence of childhood psychosis may be of the order of 1.6 to 1.9 per 100,000 child population (Gillberg & Steffenburg, 1987). However, its prevalence increases rapidly from age 14 onwards (Gillberg, Wahlström, Forsman, Hellgren, & Gillberg, 1986) with a peak incidence in the late teens and early twenties.

Substantial delays between onset of psychiatric illness and initiation of adequate treatment often occur (R. Norman, Malla, Verdi, Hassall, & Fazekas, 2004). Evidence from various countries provide estimates of time between onset of psychosis and initiation of treatment (duration of untreated psychosis, or DUP) – the means of which vary between 154 days to over 1,050 days, (Fuchs & Steinert, 2002; R. M. Norman & Malla, 2001). Lengthy treatment delays represent unnecessary prolongation of distress for patients and their families. In addition, there is some evidence that such delays may also compromise the potential for recovery once treatment is initiated (Loebel et al., 1992; McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996; R. M. Norman & Malla, 2001; Szymanski, Cannon, Gallacher, Erwin, & Gur, 1996)

A study conducted (Pradhan et al., 2001) patient primary caregivers first contact for psychiatric

care/treatment was 34.1% had chosen the psychiatrists, 29.4% the general practitioners and 26.0% had chosen faith healers and exorcists. So far as sex distribution is concerned, it was observed that there were no significant differences between male and female respondents regarding their choice of first psychiatric care/treatment for mental health problems. The first preference was for psychiatrists followed by non psychiatric allopathic doctors and faith healers. (Gureje, Acha, & Odejide, 1995) in this respect Kerala is ahead of other states where 74% of the people had directly come to the psychiatrist as their first contact. This could be attributed to the higher literacy status and mental health awareness in the state as a whole.

Research evidence also (Jain et al., 2012) found that most of the psychiatric patients had visited Faith healers – 30 (39.5%), Non-psychiatrist allopath care provider – 22 (29%) (In Indian context, non-psychiatrist allopath care provider comprises of GP, neurologists, neurosurgeons, paediatricians, compounders, nurses and other registered medical care providers) for treatment. Only 13.5% had visited the psychiatric centre directly. The mean total duration of illness (TDI) of patients was 48.8 months, mean duration of untreated psychosis (DUP) was 36.76 months and subjects had already visited, on an average, 3.93 carers before visiting any mental health professional. The mean monetary cost of the pathway was Rs. 15475.

Patients with psychotic disorders, the majority (54.5%) chose a psychiatrist as the first contact, whereas about one-third (31.8%) went to traditional faith healers or practitioners of alternative medicine. Among patients with mood disorders, psychiatrists were the first contact in more than 70% of cases, followed by non-psychiatric physicians (22.9%), with traditional faith healers or practitioners of alternative medicine being consulted by only 2 patients. Patients with organic brain disorders and headache tended to go to a non-psychiatric physician more often. Kumari et al. (2004) also reported that 60% of the caregivers first contact to the faith healers which followed by psychiatrist (20%) then general physician (18.5%) and ayurveda (1.5%), this findings showed the kind of ignorance or lack of knowledge in our society regarding the Psychiatric illness

(Nagpal, Mishra, Chadda, Sood, & Garg, 2011).

Direct access to psychiatric services after the onset of illness is not a prominent pathway. (Razali, Khan, & Hasanah, 1996). One of the most important factors responsible for faith healing is self-explanatory and magico-religious model of causation of psychiatric disorders. Thus, in the past three decades, despite significant advancement made and availability of psychiatric services in the form of community psychiatry (e.g. private sector's psychiatrist, district

mental health programs), minimal change has taken place in the myths and beliefs related to the causation of psychiatric disorders, a major determinant of pathway of care. Awareness about psychiatric disorder as one of the most important factors that could modify cultural myths regarding psychiatric disorders, consequently reaching to a favourable help seeking behaviour (Jilani, Trivedi, Dalal, Sinha, & Dhyani, 2009)

There is also a significant role of care providers in deciding the pathways to psychiatric care, the first care provider being the most important for giving direction to the pathway of care to seek further help. But the pathway to care pertinent to this segment of population is not well studied in Indian context. Thus this area was identified as to whether pathway to care is different from adults.

Methods and Materials: The study aimed to explore the pathways to care in relation to Children and Adolescents Diagnosed with First Episode Psychosis. This study was cross sectional, hospital based, time bound study from June to December, 2012. Purposive sampling technique was used to select the samples of the study. This study is conducted at Out-Patient Department of Centre for Child and Adolescent Psychiatry (CCAP) of Central Institute of Psychiatry (CIP), Kanke, Ranchi. 72 respondents were selected for study; all respondents were the primary caregivers of the patient. The tools were assessed on Socio Demographic and Clinical Data Sheet and Analysis of the delay in accessing psychiatric treatment (ADAPT): ADAPT is semi structured interview schedule, an adapted version of WHO encounter form of pathways to psychiatric care by Gater et al. (1991). Explorative research design was followed in the study.

Measures: Socio-Demographic and Clinical Data Sheet: Socio demographic and clinical data sheet was prepared or designed for this study. It had various socio-demographic variables of caregivers and patients like educational qualification, occupation, marital status, socio economic status, religion, area of residence, type of the family and family income per month. Clinical information such as age of onset, course of illness, progress of illness, any history of physical and sexual abuse, precipitating factors and diagnosis.

Analysis of the delay in accessing psychiatric treatment (ADAPT): ADAPT is semi structured interview schedule, an adapted version of WHO encounter form of pathways to psychiatric care by Gater et al. (1991). This semi structured interview schedule was modified for Indian population by Thirhalli et al. (2009). It has consisted four parts (A to D), Part-A: covers details of family members, Part-B: details of the patient scholastic information, Part-C: presenting problem at time of the help seeking,

identification of patient’s psychological problems for the first time and etc. Part-D: It covers especially modified encounter form like what steps were taken by the care giver to handle the problems and etc. The structured interview schedule was validated by the experts to suit the Indian culture. Written informed assent (consent) was sought from all the participants (primary caregivers of the children adolescents). All other ethical issues were followed during the study.

Results: Table: 1 shows that the mean age of patient was 14.8±2.0 years. Majority of the patients were males (66.7%) and 80.6% were Hindu by religion. Most of them belong to lower socio economic status (91.7 %) and came from a rural domicile (86.1%). Most of them were students (47.2%), had a nuclear family (65.3%).

Table1: Frequency distribution of the socio demographic characteristics of the patients

Sl. No	Continuous Variables		Mean + SD
1	Age in Years		14.8 ±2.0
Discreet/Categorical Variables			N = 72(%)
2	Gender	Male	48 (66.7)
		Female	24 (33.3)
3	Religion	Hindu	58 (80.6)
		Muslim	13 (18.1)
		Christian	1 (1.4)
4	Socio Economic Status	Lower	66 (91.7)
		Middle	6 (8.3)
5	Domicile	Rural	62 (86.1)
		Urban	10 (13.9)
6	Occupation patients	Nil	25 (34.7)
		Studying	34 (47.2)
		Labourer	6 (8.3)
		House hold work	6 (8.3)
		Others	1 (1.4)
7	Type of Family	Nuclear	47 (65.3)
		Joint	24 (33.3)

Table 2: Frequency distribution of the clinical characteristics of the patients

S.N.	Variables		N=72(%)
1	Course of illness	Continuous	70 (97.2)
		Fluctuating	2 (2.8)
2	Progress of Illness	Deteriorating	70 (97.2)
		Improving	2 (2.8)
3	Precipitant factors	Present	22 (30.6)
		Absent	50 (69.4)
4	History of physical and sexual abuse	Present	2 (2.8)
		Absent	70 (97.2)
5	Family history of medical and psychiatric illness	Present	39 (54.3)
		Absent	33(45.7)
6	Diagnosis	Mood disorders (Mania (34.7) and depression(5.6)	29 (40.3)
		Unspecified Non organic Psychosis	12 (16.7)
		Acute and transient psychotic disorder	15 (20.8)
		Mental Retardation with other psychotic disorder	2 (2.8)
		Others (epilepsy with psychosis, organic mood disorder, undifferentiated schizophrenia and etc).	9 (12.5)

Table 2 shows that 97.2% of patients had a continuous course and 97.2% deteriorating progress of illness. In 30.6% precipitant factors were found, history of physical & sexual abuse was present in

only 2 (2.8) patients. History of medical/psychiatric illness in the family was 54.3 % patients. The diagnosis of majority of patients was mood disorders with psychotic symptoms (40.3%).

Table 3: Information Regarding the Behaviour of Caregiver and Mental Problem of the Patient

S.N.	Domains	Mean + SD	
1	Duration of Untreated Psychosis (DUP)	155.5±304.5	
2	Time gap after the identification of “mental problem” (days)	73.6±159.0	
3	Time gap to access psychiatric services after the identification of problem (days)	43.5±101.0	
	Categorical variables	Respondents	
		N = 72 (%)	
4	Person/s who noticed change in the behaviours of the child for the first time	Mother	33 (45.8)
		Father	12 (16.7)
		Siblings	13 (18.1)
		Teachers	3 (4.2)
		Relatives	7 (9.7)
		Villagers	(1.4)
		Neighbours	1 (1.4)
		Others (friends)	2 (2.8)
5	Person/s who recognized the change as a ‘mental’ problem	Parents	25 (34.8)
		Siblings	15 (20.8)
		Villagers	9 (12.5)
		Neighbours	2 (2.8)
		Relatives	15 (20.8)
		Faith healers	1 (1.4)
		General Physician	1 (1.4)
		Others (friends, priests, religious leaders and etc)	4 (5.6)
6	Caregiver/s/Person/s who recognized the need for psychiatric care	Mother	13 (18.1)
		Father	30 (41.7)
		Siblings	15 (20.1)
		Relatives	6 (8.3)
		Villagers	5 (6.9)
		Grand parents	2 (2.8)
		Others	1 (1.4)
7	Caregiver who took care of the patient most of the times (especially in night times) before the identification & diagnosis of the problem	Mother	39 (56.1)
		Father	14 (19.4)
		Siblings	10 (13.9)
		Grand Parents	5 (6.9)
		Relatives	2 (2.8)
		Others	2 (2.8)

Table 3 shows that mean duration of untreated psychosis was 155.5 ± 304.5 days and the mean time gap after the identification of mental problem” was 73.6±159.0 days. The mean duration taken to access psychiatric services after the identification of problem was 43.5±101.0 days. Further, in majority of patients (45.8%), mother was the person to notice

change in behaviour for first time, parents were the one to recognize the problem as a mental health related in 34.8 patients and in 41.7 % patients, father was the care giver to recognize the need of psychiatric care for the patient. 56.1% mothers were taking care (especially in night times) of patient before the identification & diagnosis of the problem

Table 4: Frequency distribution of the of reason for treatment delay in seeking Psychiatric Care

S.N	Domains Response	Responses	N=72 (%)
1	Lack of proper awareness about psychiatric treatment / place & persons of treatment	No	5 (6.9)
		Yes	67 (93.1)
2	Illiteracy	No	26 (36.1)
		Yes	46 (63.9)

3	Residing in remote & inaccessible place	No	35 (48.6)
		Yes	37 (51.4)
4	Financial problem	No	24 (33.3)
		Yes	48 (66.7)
5	Remained busy in other important activities	No	32 (44.4)
		Yes	40 (55.6)
6	Fear of social stigma & isolation	No	19 (26.4)
		Yes	53 (73.6)
7	Problem in taking patient to mental health facilities/Severity of symptoms	No	44 (61.1)
		Yes	28 (38.9)
8	Poorly functional social network/low social support to family	No	29 (40.3)
		Yes	43 (59.7)
9	Others (fluctuation of the symptoms)	No	69 (95.8)
		Yes	3 (4.2)

Table 4 shows that the common reasons for delay in seeking treatment were lack of proper awareness about psychiatric treatment (93.1%), fear of social stigma and isolation (73.6%) and financial problems (66.7%).

Table 5: Frequency Distribution of the Of Sources Of Referral (Pathways) To Psychiatric Care

S.N	Source of referral for psychiatric care	Responses	N=72 (%)
1	General physician	No	39 (54.2)
		Yes	33 (45.8)
2	Family members	No	30 (41.7)
		Yes	42 (58.3)
3	Relatives	No	19(26.4)
		Yes	53(73.6)
4	Villagers	No	27 (37.5)
		Yes	45 (62.5)
5	Faith healers	No	32 (44.4)
		Yes	40 (55.6)
6	Paramedical staff	No	67 (93.1)
		Yes	5 (6.9)
7	Mental health professionals	No	65 (90.3)
		Yes	7 (9.7)
8	Others (friends, religious leaders, priests and etc),	No	68 (94.4)
		Yes	4 (5.6)

Table 5 shows that most common source of referral to psychiatric care were relatives (73.6%) followed by villagers (62.5), family members (58.3%), faith healers (55.6), General physician (45.8)

Table 6: Frequency Distribution of the First Modality of Treatment and Shifting Modality

S.N	First Modality of Treatment	N=72 (%)
1	Faith healing	44 (61.1)
2	2 General Physician	17 (23.6)
3	3 Psychiatrist	8 (11.1)
4	4 Neuro Physician	2 (2.8)
5	5 Ayurvedic and homeopathic	1 (1.4)
Shifting Modality of treatment		
1	Faith healing to Psychiatric treatment	42 (58.3)
2	2 Physician to faith healing	7 (9.7)
3	3 Faith healing along with psychiatric care	6 (8.3)
4	4 Physician to psychiatric treatment	11 (15.3)
5	5 Others (direct CIP)	6 (8.3)

Table 6 shows that most common first modality of treatment was by faith healers (61.1%) and most common shifting modality was from faith healing to psychiatric treatment (58.3%).

Discussion: The present study findings indicate that children and adolescents with first episode psychosis had mean age of 14.8 ± 2.0 and with respect to gender, majority of the patients were males (66.7%). This could be just a representation of utilization of the hospital services by male patients as compared to female patients. Another reason could be that, boys have been found to have an earlier onset of psychosis as compared to girls (Werry & Taylor, 1994). It was seen that when first episode psychosis was diagnosed before the age of 15, the male/female ratio was 3:1 but soon after the age of 15 the ratio was reduced to 1:1 (Remschmidt, 2004). It was seen that 97.2% patients had continuous course and deteriorating progress of illness with a precipitating factor being present in 30.6% patients, with respect to it (Bebbington et al., 2004) found an evidence of excess of victimizing experiences in people suffering from psychosis compared with normal population as well as with patients with other types of mental illness. In current study majority of patients have diagnosed as mood disorders with psychotic symptoms 40.3%, this finding was contrast with (R. Norman et al., 2004; R. M. Norman et al., 2002). As studies noticed schizophrenia spectrum disorder was about 67%.

In our study, the mean duration of untreated psychosis (DUP) was 155 (SD.304) days. This was bit higher than to a study conducted by (Thirthalli et al., 2011), the mean duration of untreated psychosis (DUP) was 90.2 ± 121.9 weeks. But a study conducted by (Shrivastava et al., 2012) found that the duration of illness was significantly shorter in the first contact group (17 months) compared to patients with a history of psychosis (26 months). Jain et al (2012) also found that mean DUP among the patients to be 36.76 ± 66.7 months. Reasons for the difference could be the differing role played by the family members of the patients and the stigma prevailing in the society.

The care givers took a mean time gap of 73 (SD.159) days to understand the problem as a mental health related issue. This could be due to the lack of awareness of signs and symptoms of psychiatric illness. A pilot study conducted by (Naqvi et al., 2009) to look at the generic pathway to psychiatric care found a greater delay between the onset of first symptoms and presentation to the first health carers, with a mean delay of 2.8 years. In our study, the mean duration taken to access psychiatric services after the identification of problem was 43.5 ± 101.0 days. This

could be because the care givers believed that the mental illness may cure itself, or sought consultation from faith healers, general physician, etc. before a mental health professional. The common pathways to referral for psychiatric care were relatives (73.6%) followed by villagers (62.5), family members (58.3%), faith healers (55.6), General physician (45.8), Whereas in the previous studies (Campion & Bhugra, 1997) patients suffering from illness have been reported to seek help of religious healers.

In the present study, the most common reason for delay in seeking treatment was lack of proper awareness about psychiatric treatment (93.1%), This lack of awareness could be due to the illiteracy, a rural back ground, and other socio cultural factors. Fear of social stigma and isolation was present in (73.6%) care givers by community or society, with could also be the likely reason. Another reason for delay treatment could be financial problems (61.1%) because of most of the patients were lowers socio economic status and farmers by occupation. These findings were also supported by (Naqvi et al., 2009) were almost one third of the sample reported financial difficulties as a barrier to help seeking the common reasons for delay in seeking treatment.

The most common shifting modality among the available services by the caregivers was from faith healing to psychiatric treatment (58.3%) and the most common reason for shift from one mode of treatment to another was the deterioration in previous state or no improvement (88.9%). This was also seen in previous studies ((Mishra, Nagpal, Chadda, & Sood, 2011; Salem, Saleh, Yousef, & Sabri, 2009) where most of mentally ill people were seen to contact faith/traditional healers either as their first health provider or during the course of illness at one point of time or another during the period of exacerbations of illness but most patients could not get cured by faith healers

Conclusion: It seems to be that both delay to seeking help and delay from contact with a helping mental health professionals to receiving adequate treatment are important contributors to the often reported lengthy delay in receiving treatment for children and adults with first episode psychosis, there were many socio cultural drawback factors were involved to early understanding of the problem as a mental health related issue in caregivers of the patients for psychiatric treatment. It's time to initiate mental health awareness programmes for faith healers, teachers, village leaders, religious leaders, ASHA workers and community individuals more actively for early access to psychiatric care.

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