



Experience of Stigma and Help Seeking Behaviour among the Families with a Person with Intellectual Disability

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ABSTRACT

Background: Negative evaluation based on particular features or behaviour of an individual or group is Stigma. Various medical conditions including Intellectual Disability is stigmatized in the society which has a significant implication on their treatment and rehabilitation. Stigmatization not only affects those who possess a stigmatized condition, it also impacts others people associated with stigmatized individuals (e.g., family, friends, and caregivers). Stigma is a known cause for delayed treatment seeking and a challenge for treatment and care of suffers. Therefore, it is important to study the stigma as perceived by the caregiver and their help-seeking behaviour. In this juncture, this study is intended to see the picture of above-mentioned variables in a tertiary care setting. Aim: To measure the experience of stigma and help-seeking behaviour of the families with a person with intellectual disability. Method: The study was a cross-sectional institutional based descriptive study. Criteria based sampling was employed to select 37 parents either father or mother of a person with intellectual disability who were living with a person with intellectual disability and attending the OPD of a tertiary care centre in Kolkata, India. Socio-demographic, Clinical data sheet Family Interview Schedule (FIS) and Goldberg's Pathways of Care Instrument were used to assess study variables. Result: Overall family members of a person with ID had to experience a high degree of stigma. Most (35%) preferred the first point to seek help was general physicians in private practice which remained same in the second most (27%) preferred place to seek help followed by third most (34%) preferred first place to seek help was tertiary care hospital which was the least preferred as first point. Treatment or care heavily relies on faith healer which is somewhat consistent with the other studies finding. Conclusion: Family intervention should be a center of attention to address the stigma experienced by the parents.

Keywords: Intellectual disability, mental retardation, help seeking behaviour, family, pathways of care, stigma

INTRODUCTION

Stigma is society's negative evaluation of particular features or behaviour. Cultural beliefs that define certain conditions negatively may create tainted and discounted identities for affected individuals and their families. Varied dimensions of stigmatized medical conditions e.g. leprosy¹, cancer², mental illness³⁻⁵, epilepsy^{6,7} and intellectual disability⁸ include the nature of an illness, its history, and attributed characteristics; sources of the creation and perpetuation of stigma; the nature of

the populations who are perceived to carry the illness; the kinds of treatments and practitioners sought for the condition; and how individuals with stigmatized medical conditions cope with societal insults that endanger their personal identity, social life, and economic opportunities.⁹

Stigmatization not only affects those who possess a stigmatized condition, it also impacts others. Research has shown people associated with stigmatized individuals (e.g., family, friends, caregivers) are routinely devalued purely as a result of their connection with someone with a stigmatized condition.^{10,11} This kind of devaluation seems to take place not only when there is a meaningful connection between a non-stigmatized and a stigmatized person (e.g., family relationships) but also when the connection is purely arbitrary (e.g., as a result of pure proximity.¹²

Stigmatization of mental illness in general and Intellectual Disability in particular represents main obstacles to successful

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treatment. Ignorance, prejudice and negative public attitudes towards people with Intellectual Disability and their relatives (family members) lead to a cycle of alienation and disadvantage.¹³ The most common consequences of discrimination for people with Intellectual Disability are social distancing, exclusion and being disadvantaged in regard to housing and employment opportunities.¹⁴⁻¹⁵ As a result of the stigma associated with mental illness/mental health conditions in general, and with intellectual disability in particular, people suffering from mental illness often do not accept professional help until a late stage. The fear that they will be labelled simply because they have received mental health services or treatment is too great.¹⁶⁻¹⁷

The pathway of care is the sequence of contacts initiated by the patients or families in their efforts to seek care. The pathway and the associated help seeking behaviors help us in identifying the possible sources of delay in presentation. An understanding of the way in which people seek help for mental disorders is important for planning mental health services, coordinating the psychiatric referrals, and enhancing the treatment seeking attitude.¹⁸⁻²⁰ proposed a model that people with mental health problems initiate care by consulting their general practitioners, who may refer them to psychiatric facilities. While this may be truer for well resourced western countries, it has been seen that patients from low resourced developing countries rely more often on non-professional care.²¹ Very few Indian studies have focused on the pathways or help seeking behaviors of persons with mental health problems or intellectual disability.²²⁻²⁵ Further, their samples mostly comprise common mental disorders (e.g. depression, anxiety, somatoform, etc.) presenting to clinics and only limited information is available on help seeking behaviors for psychotic disorders. When it comes to intellectual disability, there is dearth of the study. It is likely that, help seeking behaviors may have regional differences depending on accessibility to mental health services, prevailing perceptions about mental illness/intellectual disability, and other socio-cultural factors. Knowledge about the help-seeking pathways of persons with intellectual disability is pivotal in providing early interventions and thereby in supplying specialized and focused health care.²⁶ So the present study is an effort to fill the gap.

AIM

To measure the experience of stigma and help-seeking behaviour of the families with a person with intellectual disability.

METHODS AND MATERIALS

The study was a cross-sectional institutional based descriptive study. Criteria based sampling was employed to select 37 parents either father or mother of a person with intellectual disability who were living with a person with intellectual disability and attending the OPD of a tertiary care centre in Kolkata, India. and diagnosed as mental retardation as per ICD-10 criteria²⁷ by consultant psychiatrist and given

written consent to participate in the study and fulfilling inclusion and exclusion criteria were included for the purpose of data collection for present study. Socio-demographic, Clinical data sheet Family Interview Schedule (FIS)²⁸ and Goldberg's Pathways of Care Instrument²⁹ were used to assess study variables as per the set aim for the study.

RESULTS AND DISCUSSION

Socio-demographic Background

Mean age of PWID in the present study sample was 13.70 ± 6.07 where 89% study population was under the age of 18 years. It is observed age range since ID is a common developmental disorder with onset since birth. This finding is somewhat consistent with the finding of a study by Singh³⁰ where the mean age was 11.38 and standard deviation 5.76. This finding is not consistent with the finding of a study by Wagh & Ganaie (2014) where 60% PWID were between age range of 6 to 18 years and 40% were 19 to 25 years.

More than half (51.35%) of the PWID were males and rest females which is almost equal in number. Though the study did not use random sampling method but still it could be considered as an indication that MR is equally prevalent in adult men and women which was reflected in many other studies as well. Gender differences are not evident among adults³¹⁻³³ but on the contrary almost all studies report that the prevalence of mental retardation is higher among males than females especially among children less than 15 years of age.³³

Large majority 33 (89.19) of the PWID were unmarried which can be justified with the age range and disability of this population.

Majority of the PWID 23 (62.16%) were educated up to primary level in formal integrated school, followed by equal numbers 7 (18.92 %) of each were educated up to secondary and had no formal education. This particulate finding can be justified with another finding of the present study, majority (64.86%) of the PWID were having mild level of disability which can be trained another reason could be due to increasing literacy rate in (69%) West Bengal and (81%) Kolkata from where samples were drawn for the present study.³⁴ This finding is somewhat consistent with the finding of a study by Singh³⁰ where 18.5% were educated up to primary level, 32.30% up to preprimary level.

Majority of the PWID (62.16%) were educated in formal integrated education. This is very unique finding and in contrary to the Indian national scenario where only 11% of the children with disabilities between the ages of 5-18 years in urban areas and less than 1% in rural areas were enrolled in special schools. It means the children with disabilities are the most marginalized and excluded categories to receive education.³⁵ This particular study finding of the present study is contradictory with the study finding of a study by Sahay³⁶ where eighty percent of them were studying in special schools as against 20% in regular schools. Large majority (75.68%) of them were students, 5.41% PWID were house wife and 18.92 % were unemployed. No one

was having any income. These findings are self explanatory and obvious.

Clinical Profile

Majority (64.86%) of the PWID were having mild level of disability followed by moderate (24.32%) and Sever (10.81%) which is in- consistent with the finding of a study by Wagh & Ganaie³⁷ where children having mild Intellectual Disability are 11(36.7%), moderate Intellectual Disability is 10 (33.3%) and severe Intellectual Disability is 9 (30%) and also a study by Singh³⁰ where maximum (60%) children had moderate level of mental retardation, 13.50% had mild level, and 26.20 % had severe level of mental retardation.

The mean age of getting diagnosis for PWID in the present study sample was 4.61 ± 5.57 years. Around 78% were diagnosed or identified within the age of 6 years this could be seen as a result of various affords. It is only in the recent years that early identification of persons with mental retardation. Early identification and prevention is the first step towards better care and rehabilitation. Over the past two decades, the parents and caregivers have become more and more aware of the need for services for their wards with mental retardation. Trained professionals have also become more available now.³⁸

Mean of and duration of treatment was 5.63 ± 5.39 years and the mean duration of treatment at the present institution was 1.35 ± 1.79 years. These findings are obvious.

Majority (59.46%) of the PWID were on medications. Less number 6 (16.22%) of PWID were having any side effect of medications. This could be because the due to the co-morbid medical conditions.

More than one third (35.14%) PWID were having epilepsy followed by (16.22%) of the PWID psychiatric symptoms/diagnosis, (5.41%) were having physical disability and (2.70%) was having hearing impairments. The present study finding is not consistent with the finding of a study³⁰ where 91% study population were having some co-morbid conditions. Co-morbid conditions are common in this population.

Majority (62.16%) of the PWID had no positive family history of mental retardation. The present study finding is somewhat consistent with the finding of a study by Singh (2008) where 86.2% of the MR children did not have any history of mental retardation in the family.

Mean of no. of hospitalization was $.43 \pm .65$ this is not high one hospitalization could be obvious and also could be explained with other findings of the present study that is co-morbid medical condition.

At most half, 51.35% PWID were not undergoing any psychosocial intervention reason of not undergoing any psychosocial treatment could be limited psychosocial treatment services availability like other part of the country³⁹ or lack of awareness about this kind of treatment options.

Family Background

Mean age of the fathers was 44.67 ± 9.75 years where as for mothers it was 39.54 ± 10.49 this finding is somewhat consistent with the finding of a study by Singh (2008) where

parents' age range was 21 - 63 with the mean of 37.43, and standard deviation 8.78.

More than one third (35.14%) both parents were educated up to primary level followed by 32.43% mothers and 24.32% fathers were educated up to secondary level, 18.92% mothers and 16.22% fathers were educated up to higher secondary, 13.51% fathers and 8.11% mother up to graduation, 10.81% fathers and 5.41% mothers had no formal education. This finding is not consistent with the finding of a study³⁰ where Most of the parents (41.6%) were educated up to graduation or more, 30.8% were educated up to pre-university, 12.3% up to primary level, while 15.4% were uneducated.

In regards to employment, large majority (83.78%) of the fathers were employed as - self employed (35.14%), fulltime employed (32.43%), part time employed (16.22%). 10.81% were retired and only 5.41% were unemployed. Whereas three fourth (75.68%) mothers were house wives followed by 18.92% self-employed and 5.41% were full time employed. This finding is not consistent with the finding of a study³⁰ where majority of, that is, 43.1% were house wives, 23.1% were employed, 13.8% were business persons, and 20% were laborers and farmers.

Large majority (78.38%) of them were Hindu followed by Muslim (21.62%) this could be because India is a country where majority of the people are Hindus.⁴⁰ Majority (70.27%) of them hailing from urban areas followed by less than half (29.73%) were from rural area this finding is somewhat consistent with the finding of a study by Singh where most of them belonged to urban background (63.1%), while 36.9% hailed from rural background and also a study by Wagh & Ganaie³⁷ where 60% study population were urban and 40% were from rural areas.

With changing family type, India is bending towards nuclear family; the study population was not exception in this regard. Majority (62.16%) of them from nuclear families followed by 37.84% were from joint family. This finding is also somewhat consistent with the finding of a study³⁷ where 70% parents having nuclear family are and 30% parents having joint family. Even though, families were nuclear the number of children were not one or two the mean number of family members was 5.05 ± 3.18 ranging from 2 to 20 members.

Mean of family income was Rupees 7135 ± 6080 which indicated they belong to lower socio-economic status. This finding is also somewhat consistent with the finding of a study by Sahay et al.³⁶ where the family incomes of most of the children with intellectual disabilities (75.6%) were below RS 6500/ per month.

Experience of Stigma

From table 1 in the present study population, overall family members of a person with ID had to experience a high degree of stigma. All family members of study population had the feeling of grief or depression (because of one person was having ID in the family). Various dimension of stigma experienced by the family members of a person with ID. 92% family members sought out families with a person with ID. 78% felt it might be construed as their fault that a person was suffering from ID in the family.

Table 7 Stigma Experienced by the Family Members

Cortex: 0 = Not at all, 1= Sometime, 2 = Often, 3 = A lot

Stigma Items	0	1	2	3	1+2+3	%
Felt grief or depression	0	6	11	20	37	100.0
Sought out families with a person with ID	3	14	12	8	34	91.89
Felt it might be your fault	8	10	8	11	29	78.38
Helped other people to understand	8	14	10	5	29	78.38
Spend time worrying	11	5	11	10	26	70.27
Ashamed / Embarrassed about it	11	4	10	12	26	70.27
Neighbours would treat differently	11	4	11	11	26	70.27
Worry that you would be blamed	12	7	11	7	25	67.57
Worry that neighbours would avoid	13	7	11	6	24	64.86
Worried about taking him/her out	14	3	9	11	23	62.16
Explaining to others that he/she is not crazy	14	12	5	6	23	62.16
Marriage	17	5	8	7	20	54.05
Need to hide fact	18	7	7	5	19	51.35
Total Mean Score ± SD (Range 2 – 42)						19.76 ± 10.17

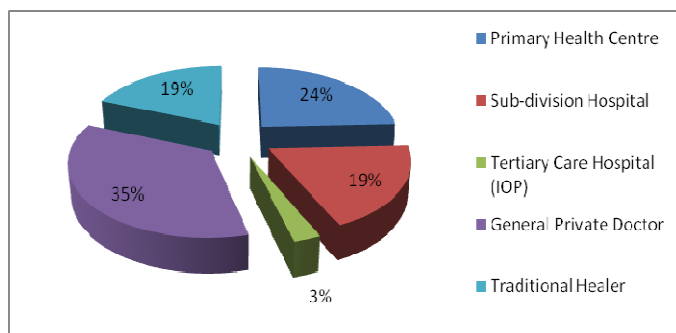
70% family members spent time worrying about their PWID, they felt ashamed/ embarrassed about their PWID and feared that ‘neighbours would treat them differently. 68% family members worried that they would be blamed’ for a person was having ID in the family. 65% family members worried that neighbour’s would avoid them. 62% family members worried about taking him/her (PWS) outside the home and helped other people to understand that his/her relative (with ID) was not crazy. 54% family members made effort to keep (ID) a secret and 51% were concerned about the marriage of their PWID wards. 96% family members needed to hide the facts. Other studies also reported various aspect of stigma experienced by the family members of a person with ID.⁴¹⁻⁴⁴

Pathways of Care

Table 8 Pathways of Care

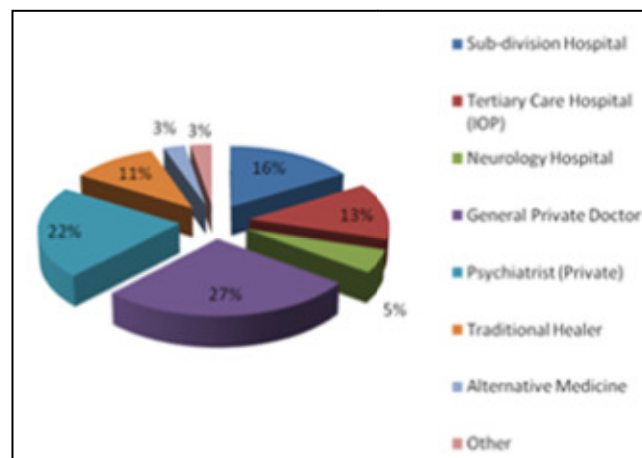
Place to Seek Help	Care Seeking Order									
	1 st	2 nd	3 rd	4 th	5 th	6 th	7 th	8 th	9 th	10 th
Primary Health Centre	9	-	-	-	-	-	-	-	-	-
Sub-division Hospital	7	6	1	-	-	-	-	-	-	-
Tertiary Care Hospital	1	5	11	10	9	-	1	-	-	-
Neurology Hospital	-	2	3	4	-	-	-	-	-	-
General Private Doctor	13	10	2	-	-	-	-	-	-	-
Psychiatrist (Private)	-	8	2	2	-	-	-	-	-	-
Traditional Healer	7	4	9	1	-	-	-	-	-	-
Alternative Medicine	-	1	1	4	1	1	-	-	-	-
Other	-	1	4	-	1	-	1	-	-	-

Figure 1 First Preferred Point to Seek Help



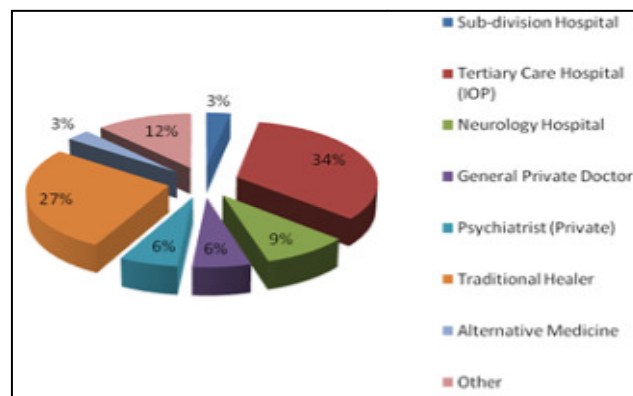
In the present study population, most (35%) preferred first place to seek help was general physicians in private practice followed by primary health centre (24%), traditional healer/sub-division hospital (19%) each and tertiary care hospital (3%).

Figure 2 Second Preferred Point to Seek Help



Second most (27%) preferred first place to seek help was also general physicians in private practice followed by psychiatrist in private practice (22%), sub-division hospital (16%), tertiary care hospital (13%), traditional healer (11%), Neurologist in hospital settings (5%) and rest alternative medicine/others (3% each).

Figure 3 Third Preferred Point to Seek Help



Third most (34%) preferred first place to seek help was tertiary care hospital which was the least preferred as first point followed by traditional healer (27%), others (13%), Neurologist

in hospital settings (9%), psychiatrist/ general physicians in private practice (6% each), sub-division hospital/alternative medicine (3% each).

The present study findings are not consistent with the study conducted by Chakraborty et, al. (2014) on pathways to care for children with specific learning disability and mental retardation and found multiple carers including traditional healers substantiating the strong belief for supernatural causation of developmental disorders in India. Jain et al. (2012) also reported that the pathway to psychiatric care heavily relies on faith healer which is somewhat consistent with the present study findings.

CONCLUSION

Overall family members of a person with ID had to experience a high degree of stigma.

Most preferred first place to seek help was general physicians in private practice followed by primary health centre and traditional healer/sub-division hospital each and tertiary care hospital. Second most preferred place to seek help was also general physicians in private practice followed by psychiatrist in private practice, sub-division hospital, tertiary care hospital, traditional healer and rest others. Third most preferred place to seek help was tertiary care hospital which was the least preferred as first point followed by traditional healer, others and rest others.

Treatment or care heavily relies on faith healer which is somewhat consistent with the other studies finding.

This study can be taken further with large sample size and random sampling technique for better generalizability

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