

A Study of Profile of Disability Certificate Seeking Patients with Schizophrenia Over a 5 Year Period

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ABSTRACT

Background: Schizophrenia has been identified as one of the most disabling condition known to mankind. Until recently there was no published literature on disability certification seeking behavior of patients diagnosed with schizophrenia. The current study aimed at understanding the profile of patients diagnosed with schizophrenia seeking disability certification for a tertiary level multispecialty hospital in India. **Materials and Methods:** The study was carried out at the Psychiatry department for a tertiary care hospital in India. The evaluation of the subjects was carried out in the presence of a primary care giver. First, the diagnosis was established using International Statistical Classification of Diseases and Related Health Conditions (ICD)-10. Subsequently, the disability was assessed using Indian Disability Evaluation Assessment Scale (IDEAS). Data were analyzed using SPSS (Statistical Package for Social Sciences) software version 17. **Results:** A total of 169 subjects seeking disability certification over the study period of 5 years were diagnosed with schizophrenia. Out of 169 subjects 132 (78.1%) were male and 37 (21.9%) were female. There was a statistically significant difference in the marital status of the male and female study subjects. Family history of psychiatric illness was positive in 9.8% of male subjects and 10.8% of female subjects. There was no significant difference between male and female subjects for the duration of illness and duration of being on treatment. Male and female subjects did not differ significantly on the IDEAS global score, personal care, interpersonal interaction, and understanding and communication domains of IDEAS. The two groups differed significantly on the work domain. **Conclusions:** Majority of patients with schizophrenia seeking disability certificate continue to be male. However, male and female subjects tend to differ very little on various socio-demographic and illness related variables. The levels of disability are also comparable among males and females. However, the work related disability is relatively higher among males and females continue to be financially dependent on the family members.

Key words: Disability, India, schizophrenia

INTRODUCTION

'Disability' has been assigned as the umbrella term to include impairments, activity limitations

or participation restrictions by The International Classification of Functioning (ICF) Disability and Health. The older concept of 'disability' along with the terms 'impairment' and 'handicap', as described by ICF, have been subsumed under the concept of 'Activity and Participation'.^[1]

Neuropsychiatric disorders continue to be leading contributors to the global burden of disease. As per the World Health Report, 2001 mental illnesses accounted for 25% of total disability and 16% of the total burden.^[2] Among women aged 15-44 years, mental disorders constitute three of the 10 leading causes of

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disease burden in low-and middle-income countries, and 4 of the leading 10 in high-income countries.

As per the Census of India, 2001 there are an estimated 2,263,821 (for a population of 1,028,610,328) people suffering from disability due to mental illness in the country. Mental disorders rank third among the five leading contributors to disability in India.^[3] However, a recent community-based study in India found mental disability to be the most common type of disability accounting for 36.7% of total disability.^[4]

Schizophrenia has been identified as one of the most disabling condition known to mankind. As per the estimates for global burden of a disease study, schizophrenia is the sixth leading cause of years lived with disability.^[5] It usually starts during young age and is frequently associated with deterioration from the previous level of functioning. This deterioration is reflected in various functional deficits leading to social isolation and poor occupational functioning.^[6] It is also being increasingly recognized that disability is one of the outcome indices for chronic illnesses such as schizophrenia.

The Indian literature on disability in schizophrenia has focused on patients seeking treatment in out-patient setting,^[7,8] in patient setting^[9] and community setting.^[10] However, till recently there was no published literature on disability certification seeking behavior of patients diagnosed with schizophrenia. A recent study from Karnataka explored the utilization of disability benefits by those who have been issued disability certificates.^[11]

The current study aimed at understanding the profile of patients diagnosed with schizophrenia seeking disability certification for a tertiary level multispecialty hospital in India. The findings of this study are expected to provide valuable information on various socio-demographic and illness related variables of these individuals.

MATERIALS AND METHODS

The current study aimed at assessing the profile of subjects diagnosed with schizophrenia seeking disability certification. Additionally it aimed at assessing the various socio-demographic and illness related variables among these individuals.

The study was carried out at the Psychiatry Department for a Tertiary Care Hospital in India. The Department of Psychiatry is a designated nodal entre for disability certification. All the applications received for disability certification are given an appointment for detailed evaluation. We here present the findings form review

of cases seeking disability certification over a 5 year period. All subjects seeking disability certification over the study period.

The evaluation of the subjects was carried out in the presence of a primary care giver. Detailed history taking and mental status examination was carried out as part of this evaluation process. The evaluation board comprised of three qualified psychiatrists with at least 3 years of post-senior residency experience in psychiatry. First, the diagnosis was established using ICD-10 (International Statistical Classification of Diseases and Related Health Conditions). Subsequently, the disability was assessed using Indian Disability Evaluation Assessment Scale (IDEAS). All the cases diagnosed with schizophrenia were included in the final analysis.

Study instrument

Socio-demographic information from all the subjects was collected using a pre-approved semi-structured proforma. Subsequently they were diagnosed using ICD-10.

All the study subjects were assessed using IDEAS. IDEAS are approved by the Government of India for documenting the level of disability due to mental illness. It assesses disability under four domains: Self-care, interpersonal activities (social relationships), communication and understanding, and work. Each item is scored between 0 and 4, i.e., from no to profound disability, adding scores on 4 items gives the 'total disability score'.

Global disability score is calculated by adding the 'total disability score' and MI2Y score (Months Ill in 2 years- a score ranging between 1 and 4, depending on the number of months in the last 2 years the patient exhibited symptoms). Global disability score of 0 corresponds to 'no disability', a score between 1 and 7 corresponds to 'mild disability', and a score of 8-13 corresponds to 'moderate disability', a score between 14 and 19 corresponds to 'severe disability', and a score of 20 corresponds to 'profound disability'.

An IDEAS is a well-validated instrument and is being used across the country for disability evaluation in psychiatric disorders. The alpha value for the scale has been found to be 0.8682, indicating good internal consistency between the items. It has good criterion validity and at face validity. Criterion validity of the scale has been established by comparing IDEAS with Schedule for the Assessment of Psychiatric Disability which has been standardized in India.^[7]

Statistical analysis

Data were analyzed using SPSS (Statistical Package

for Social Sciences) software version 17. Descriptive analysis including frequency distribution was carried out for the socio-demographic variables. Categorical variables were analyzed using Chi-square test and continuous variables were analyzed using parametric tests. These included independent sample *t*-test for in-between group differences for male and female subjects; and family history positive/negative subjects. Further, correlation between different illness variables and IDEAS scores was carried out using Pearson's correlation coefficient. The level of statistical significance was kept at $P < 0.05$ for all these tests.

Conditions of anonymity and confidentiality as recommended were strictly adhered to during the course of the study and data reporting.

RESULTS

A total of 169 subjects seeking disability certification over the study period of 5 years were diagnosed with schizophrenia. It constituted around 81% of all the disability seeking patients over this period.

Out of 169 subjects 132 (78.1%) were male and 37 (21.9%) were female. The mean age of male subjects and female subjects were 36.89 (standard deviation (SD) ± 9.67) years and 39.56 (SD ± 11.79) years, respectively. Majority of the study subjects were literate [Table 1]. Only around 5.3% of males and 10% of females were illiterate. Majority of the study subjects (93.9% males and 86.4% females) were from an urban setting.

There was a statistically significant difference (Chi-square=25.27, $df=4$, $P < 0.05$) in the marital status of the male and female study subjects. While the majority of male subjects were unmarried (62.1%) and an equal proportion of female subjects were married and unmarried (35.1% each). Also, 18.9% of the female subjects were either separated or divorced. In comparison, only 8.3% of male subjects were either separated or divorced.

There was a statistically significant difference in the employment status of the male and female subjects (Chi-square=7.84, $df=2$, $P=0.02$). While 17.4% of male subjects were employed, none of the female subjects was currently employed.

Around 56.7% of the female subjects were from a lower socio-economic background. The rest belonged to middle socio-economic status. In comparison, 15.9% of the male subjects belonged to lower socio-economic status, with the rest belonging to middle socio-economic status. This difference was not statistically significant (Chi-square=3.23, $df=1$,

Table 1: In-between group differences for male and female subjects for socio-demographic variables

Variable	Gender		Chi-square value	df	P value
	Male (n=132)	Female (n=37)			
Educational qualification			6.74	5	0.24
Illiterate	7	4			
Under 5 th standard	12	6			
6 th to 8 th standard	18	7			
9 th to 12 th standard	49	13			
Graduate	37	7			
Post-graduate	9	0			
Residence			2.26	1	0.13
Rural	8	5			
Urban	124	32			
Marital status			25.27	4	0.00*
Married	39	13			
Unmarried	82	13			
Separated	1	3			
Divorced	10	4			
Widow	0	4			
Employment status			7.84	2	0.02*
Employed	23	0			
Unemployed	108	37			
Student	1	0			
Family type			1.50	2	0.47
Nuclear	68	23			
Joint	63	14			
Alone	1	0			
Socio economic status			3.23	1	0.07
Lower	53	21			
Middle	79	16			
Primary earning member			8.99	2	0.01*
Parents	80	18			
Self	14	0			
Other family members	38	19			

*Statistically significant difference at $P < 0.05$

$P=0.07$). A significantly higher (Chi-square=8.99, $df=2$, $P=0.01$) percentage of male subjects (10.6%) were the primary earning member of the family as compared to female subjects (none).

Family history of psychiatric illness was positive in 9.8% of male subjects and 10.8% of female subjects [Table 2]. Of these, around 76.4% of the family members were suffering from schizophrenia.

There was no significant difference between male and female subjects for the duration of illness ($t=-1.20$, $P=23$, 95% CI-4.62-1.12) and duration of being on treatment ($t=-0.86$, $P=38$, 95% CI-4.03-1.57). Disability was assessed using IDEAS. The mean global score on IDEAS were 12.29 SD ± 2.67 and 11.78 SD ± 2.82 for male and female subjects, respectively [Figure 1 and Table 3].

Male and female subjects did not differ significantly

on the IDEAS global score ($t=1.01, P=31, 95\%$ CI-0.48-1.51), personal care ($t=0.68, P=0.49, 95\%$ CI-0.20-0.41), interpersonal interaction ($t=-0.35, P=0.72, 95\%$ CI-0.33-0.22), and understanding and communication ($t=-0.16, P=0.87, 95\%$ CI-0.33-.28) domains of IDEAS. The two groups differed significantly on the work domain ($t=3.92, P<0.05, 95\%$ CI-0.43-1.30). The disability on work domain was higher for male (mean=3.38 SD±1.21) as compared to female (mean=2.51 SD±1.09) subjects. Around 59.8% of male subjects and 56.7% of female subjects were suffering from moderate level of disability. Severe

disability was found in 34.8% of male subjects and 35.1% of female subjects [Table 2].

There was a significant positive correlation between total duration of illness and global IDEAS score ($r=0.287, P=0.001$) and duration for seeking treatment and global IDEAS score ($r=0.242, P=0.005$) for male subjects [Table 4].

However, no such correlation was observed for female subjects [Table 5].

Additionally, the subjects with or without a family history of psychiatric illness did not differ on various domains of IDEAS scale as well as global IDEAS score [Table 6].

Table 2: In-between group differences for male and female subjects for illness related variables

Variable	Gender		Chi-square value	df	P value
	Male	Female			
Family history of psychiatric illness			0.03	1	0.53
Present	13	4			
Absent	86	35			
Family history of psychiatric illness-type			4.81	3	0.18
Schizophrenia	11	2			
BPAD	1	0			
MR	1	1			
OCD	0	1			
Severity of disability (as assessed by IDEAS)			0.73	2	0.69
Mild disability	6	3			
Moderate disability	79	21			
Severe disability	46	13			

BPAD – Bipolar affective disorder; MR – Mental retardation; OCD – Obsessive compulsive disorder; IDEAS – Indian disability evaluation assessment scale

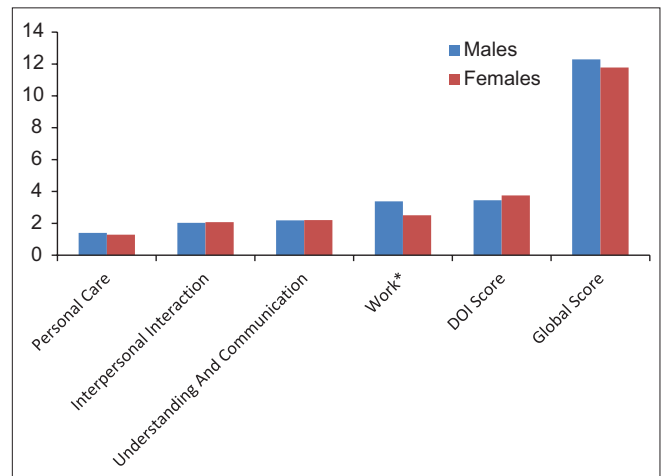


Figure 1: Mean scores on various domains of IDEAS for male and female subjects. *Statistically significant difference at $P<0.05$

Table 3: In-between group differences for male and female subjects for age, illness related and IDEAS variables

Variable	Gender	N	Mean	Standard deviation	t value	P value	95% CI		
							Lower limit	Upper limit	
Age	Male	132	36.89	9.67	-1.41	0.16	-6.40	1.06	
	Female	37	39.56	11.79					
Duration of illness (in years)	Male	131	13.06	7.548	-1.20	0.23	-4.62	1.12	
	Female	37	14.81	8.69					
Duration of treatment (in years)	Male	131	11.61	7.22	-0.86	0.38	-4.03	1.57	
	Female	37	12.83	8.92					
IDEAS scores	Personal care	Male	131	1.40	0.87	0.68	0.49	-0.20	0.41
	Female	37	1.29	0.70					
Interpersonal interaction	Male	131	2.03	0.72	-0.35	0.72	-0.33	0.22	
	Female	37	2.08	0.89					
Understanding and communication	Male	131	2.19	0.82	-0.16	0.87	-0.33	0.28	
	Female	37	2.21	0.88					
Work	Male	131	3.38	1.21	3.92	0.00*	0.43	1.30	
	Female	37	2.51	1.09					
DOI score	Male	131	3.45	0.82	-1.86	0.06	-0.63	0.01	
	Female	37	3.75	1.06					
Global score	Male	131	12.29	2.67	1.01	0.31	-0.48	1.51	
	Female	37	11.78	2.82					

IDEAS – Indian disability evaluation assessment scale; DOI – Duration of illness; CI – Confidence interval; *Statistically significant difference at $P<0.05$

DISCUSSION

The current study aimed at assessing the profile of patients with schizophrenia seeking disability certification at a Tertiary Care Multispecialty Hospital in India. Additionally it aimed at assessing the various socio-demographic and illness related variables among these individuals.

The existing Indian literature on disability among patients diagnosed with schizophrenia has focused on patients seeking treatment in out-patient, in-patient and community settings.^[7-10] There is limited literature on profile of patients seeking disability certification in the country.

We analyzed a total of a total of 169 subjects seeking

Table 4: Correlation between socio-demographic, illness variables and IDEAS score for the male subjects

Variable	Personal care	Interpersonal interaction	Understanding and communication	Work	Global score
Age					
<i>r</i> value	0.087	0.074	-0.017	0.018	0.122
<i>P</i> value	0.326	0.402	0.850	0.840	0.164
Duration of illness (in years)					
<i>r</i> value	0.120	0.103	-0.011	0.127	0.287*
<i>P</i> value	0.173	0.244	0.905	0.149	0.001
Duration of treatment (in years)					
<i>r</i> value	0.074	0.058	-0.049	0.116	0.242*
<i>P</i> value	0.402	0.509	0.575	0.186	0.005

*Statistically significant correlation at $P < 0.05$; IDEAS – Indian disability evaluation assessment scale

Table 5: Correlation between socio-demographic, illness variables and IDEAS score for the female subjects

Variable	Personal care	Interpersonal interaction	Understanding and communication	Work	Global score
Age					
<i>r</i> value	-0.209	-0.126	-0.068	-0.128	-0.091
<i>P</i> value	0.215	0.458	0.690	0.449	0.592
Duration of illness (in years)					
<i>r</i> value	-0.122	-0.262	-0.222	-0.176	-0.128
<i>P</i> value	0.470	0.117	0.187	0.297	0.450
Duration of treatment (in years)					
<i>r</i> value	-0.267	-0.326*	-0.298	-0.221	-0.239
<i>P</i> value	0.110	0.049	0.074	0.188	0.154

*Statistically significant correlation at $P < 0.05$; IDEAS – Indian disability evaluation assessment scale

Table 6: In-between group differences for the study variables for subjects with and without a family history of psychiatric illness

Variable	Family history of psychiatric illness	N	Mean	Standard deviation	<i>t</i> value	<i>P</i> value	95% CI	
							Lower limit	Upper limit
Age	Present	17	35.94	9.65	-0.65	0.51	-6.86	3.44
	Absent	152	37.65	10.27				
Duration of illness (in years)	Present	17	15.17	9.46	0.96	0.33	-2.02	5.87
	Absent	152	13.25	7.62				
Duration of treatment (in years)	Present	17	13.94	9.63	1.17	0.24	-1.55	6.13
	Absent	152	11.64	7.36				
IDEAS scores								
Personal care	Present	17	1.29	0.98	-0.44	0.65	-0.52	0.32
	Absent	152	1.39	0.82				
Interpersonal interaction	Present	17	2.00	0.86	-0.23	0.81	-0.43	0.33
	Absent	152	2.04	0.75				
Understanding and communication	Present	17	2.17	0.88	-0.10	0.91	-0.44	0.40
	Absent	152	2.19	0.83				
Work	Present	17	3.41	2.18	0.77	0.43	-0.37	0.87
	Absent	152	3.16	1.09				
DOI score	Present	17	3.58	0.87	0.34	0.73	-0.37	0.52
	Absent	152	3.50	0.89				
Global score	Present	17	11.94	3.15	-0.38	0.69	-1.64	1.10
	Absent	152	12.21	2.66				

DOI – Duration of illness; IDEAS – Indian disability evaluation assessment scale; CI – Confidence interval; *Statistically significant difference at $P < 0.05$

disability certification over the study period of 5 years was diagnosed with schizophrenia. Schizophrenia remains the most common diagnosis among previous Indian studies on disability among treatment seeking psychiatric patients. Kashyap *et al.*^[11] reported 65.3% of the subjects to be diagnosed with schizophrenia in their total sample of 285 over a 3 year period.

However, affective disorders have been found to be the most common cause of disability among not treatment seeking individuals in community based studies.^[10] In spite of comparatively lower prevalence than other mental disorders schizophrenia continues to be over represented among treatment seekers in hospitals.^[12]

In the current study, an overwhelming majority of study subjects were male. In a community based epidemiological survey for disability in rural Karnataka, females constituted 68% of individuals with mental disability.^[10] In a recent study from Karnataka, females constituted 49.1% of all disability certificate seeking individuals over a 3 year period.^[11] Similarly, in a study among long stay patients diagnosed with schizophrenia 67.86% were male. In another study from Assam, 31.6% of the study subjects were female.^[13]

While previous Indian studies have reported relatively later help seeking for female patients suffering from schizophrenia, the same is not reflected in the findings of the current study.^[14] In the present study male and female subjects did not differ significantly with regards to age at presentation, total duration of illness and duration since seeing treatment. The study by Kujur *et al.*^[14] also observed a significant difference in marital status of male and female patients with schizophrenia with majority (57.7%) of women were separated from their husbands. A significantly higher proportion of female subjects were divorced or separated in the current study.

Previous studies from the west have documented moderate disability in most of patients diagnosed with schizophrenia irrespective of the setting.^[15] In the current study also moderate disability was most common followed by severe disability. Indian studies have revealed the disability among patients with schizophrenia to moderate to severe as early as 2-5 years after illness onset.^[7] In a study from Assam, 64% of patients suffering from schizophrenia and 30% of those suffering from bipolar affective disorder had severe disability as per the IDEAS.^[13] Also the disability tends to remain stable over time with minimal fluctuations.^[8] However, an Indian study among non-treatment seeking individuals in a community setting found mild disability as the most common.^[10]

In the present study, the highest disability for both

male and female subjects was observed in the work domain of IDEAS. Previous Indian studies have also reported occupational disability as the most disabling of all the categories.^[16] Additionally, the least disability observed for personal care (for both male and female subjects) was also in keeping with similar observations in previous studies. However, another Indian study conducted in a mental hospital setting found the highest level of disability for understanding and communication domain of World Health Organisation Disability Assessment Schedule II (WHODAS II).^[9]

Disability in schizophrenia has been found to be affected by characteristics like age of onset and duration of illness among other factors.^[17] In a previous Indian study from Ranchi it was found that duration of illness has a significant correlation with personal areas of disability and age of onset has significant positive correlation with personal and occupational area of disability.^[18] However, in the current study a significant positive correlation between total duration of illness and global IDEAS score was observed only for the male subjects. The female subjects did not exhibit any such correlation.

A previous study by Thara *et al.*^[19] found a significantly higher global disability and occupational disability among male patients suffering from schizophrenia as compared to the female patients. However, the two did not differ for disability on other domains including self-care, social withdrawal and social contact. In the present also the male and female subjects differed significantly only on the work domain of IDEAS. No significant differences were observed for personal care, interpersonal interaction and understanding and communication domains. Also, there was no significant difference on the global IDEAS score for male and female subjects.

Stigma, poor knowledge about the IDEAS, fear of misuse of certificates, discomfort to approach government hospitals, time constraints, rigid negative thinking about legal issues, denial of disability have been specified as some of reasons for underutilization of disability certification.^[11] Lack of education among disabled is an important barrier for effective delivery of services. According to National Sample Survey Organization, 2002 54.7% of disabled belonged to illiterate category.^[20] Interestingly only 12.2% of the subjects in the present study were illiterate.

Gender has been found to be an important determinant of help seeking for mental disorders.^[21] Women with common mental disorders were more likely to have sought some form of help than men in studies from western setting.^[22] However, the situation is different in

developing countries such as India. Due to socio-cultural factors women depend on men with regards to help seeking for their mental health problems. Researchers has revealed that those closest to the individual play an influential role in whether or not an individual seeks mental health services when experiencing distressing symptoms.^[23]

Multi-ethnic studies have reported that Asian patients with psychiatric illness tend to show the longest delay in help seeking. More intensive, extended and persistent family involvement is a possible reason for the delay in seeking help by these individuals.^[24]

The present study offers some interesting and important insights in to disability certification seeking behavior of patients diagnosed with schizophrenia. There is a relatively long gap between the onset of illness and disability certification. In spite of regulatory threshold of 2 years, patients take a long time before seeking disability certification. This would mean a delay in disability benefits as well for these individuals. Also, all the female subjects in the present study were not gainfully employed and were financially dependent on the family. Also, a significant greater proportion of them were either divorced or separated. This was reflection of the impact of their illness on marital status. However, majority of males still manage to continue in marital relation. The findings also suggest a relatively early stabilisation of disability among females as the duration of illness was not found to be correlated with global IDEAS score. However, there was a significant correlation between these two variables for male subjects. Relatively later impact of disorder on employment status is a likely possible reason for this observation. Lack of impact of presence of psychiatric illness in another family member does not impact the disability seeking behavior of the study subjects. This is a worrisome finding and it reflects poor education of family with regard to the provisions of disability certification and disability benefits available.

There is a need to disseminate information related to impact on disabled, community mobilization, opportunity for education, opportunity for work, transfer skills to community level, program activities, and involvement of disabled people. Also, research with respect to services, fund allocation, cost-effectiveness, manpower, training, and technical aid of disabled people should be strengthened. A special emphasis should be placed on providing rehabilitation services and disability benefits to the unreached persons with disabilities living in rural areas and small towns of the country.^[25]

Positive impact of disability assessment camps on disability certification seeking behavior has been

documented in India.^[11] Even those who have received disability certification do not utilize the disability benefits offered by the government. The underutilization is even more prominent in rural areas with disability pension being the most utilized benefit.

Strengths of the study

The current study presented findings from a 5 year period. This is the second study of this nature from India. We included all the subjects diagnosed with schizophrenia seeking disability certification over the study period. There was no missing data. Assessment was carried out using a standardized Indian instrument that has been used previously in Indian settings.^[26]

Limitations of the study

However, there are certain limitations as well. The findings are from a single setting. The results cannot be extrapolated to other settings. Also, the findings need to be replicated in multisite studies before they could be generalized. Also, it would be informative to review these subjects over time to assess the stability of disability level. Additionally, information on the utilization of disability benefits subsequent to certification should also be assessed in future studies.

CONCLUSIONS

Majority of patients with schizophrenia seeking disability certificate continue to be male. However, male and female subjects tend to differ very little on various socio-demographic and illness related variables. There are significant difference in the likely impact of schizophrenia on marital status of males and females. The levels of disability are also comparable among males and females. However, the work related disability is relatively higher among males and females continue to be financially dependent on the family members.

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