

## Self, Proxy and Interviewer Rated Versions of World Health Organization Disability Assessment Schedule (WHODAS) 2.0 among the Patients of Bipolar Affective Disorder

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### ABSTRACT

**Background:** World Health Organization Disability Assessment Schedule (WHODAS 2.0) is an International Classification of Functioning based multidimensional instrument was developed for measuring disability among the patients with bipolar affective disorder. **Objective:** The present study aims to check the concordance amongst the self, proxy and interviewer administered version of the WHODAS 2.0 among the patients with bipolar affective disorder. **Materials and Methods:** The study was cross sectional in nature. Thirty samples of patients with bipolar affective disorder as per ICD-10 criteria were selected using a consecutive sampling technique. Patients above 18 years of age with total duration of illness of at least more than 2 years were included. Those who refused consent for the study were excluded. The study was conducted at Outpatient department (OPD) of Mental Health Institute (MHI) and Department of Psychiatry, Government Medical College and Hospital Sector 32, Chandigarh and used self, proxy and interviewer administered version of WHODAS 2.0. The data was analyzed using SPSS-23.0 software. **Results:** The study indicated that there was no significant difference found among the self, proxy and interviewer-based assessment for most of the items however the mean score of interviewer rated version was higher in comparison to self and proxy rated versions of WHODAS 2.0. **Conclusion:** The overall inter-reliability of WHODAS 2.0 among the self, proxy and interviewer was moderate. There was no significant difference among the self, proxy and interviewer assessment for most items. This study highlights the fact that service users can also carry out an objective self-assessment of disability thus upholding the principles of advanced directives as envisaged under Mental Health Care Act, 2017.

**Keywords:** WHODAS 2.0, Bipolar Affective Disorder, Self, Proxy, & Interviewer

### INTRODUCTION

Bipolar affective disorder is a serious public health issue that causes significant Psychosocial and occupational impairment (Jimenez et al., 2018). The global prevalence of people with this condition has raised rapidly in the last thirty years, from 32.7 million in 1990 to 48.8 million in 2018, an increase of 49.1% (Ferrari et al., 2016). The Global Burden of Disease study establishes that among the entire population with disability (i.e. estimation of years due to disability), bipolar affective disorder is the sixth and third cause in men and women, respectively (Feigin et al., 2018). Patients with bipolar affective disorder tend to have difficulties at several levels (Elgie et al., 2007). Their productivity at work is often decreased and they are dismissed more often (Bonnin et al., 2013). They generally have fewer social interactions and are reduced social network and therefore have less likelihood of accomplishing social milestones such as marriage (Rosa et al., 2009). They find it difficult to express their opinions and to communicate comfortably; and they show persistent problems in carrying out daily activities such as certain domestic tasks (Calabrese et al., 2003).

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Patients with bipolar affective disorder have problems in a wide range of diverse day to day situations. Tools for assessing functioning and disability are therefore very important for estimating levels of functional impairment in the occupational and Psychosocial domains, among others (Gitlin et al., 2017). There are several instruments that have been used to measure functioning in persons with bipolar affective disorders viz. Global Assessment of Functioning scale, the Short Form Health Survey-36, the Life Functioning Questionnaire, and the Social Adjustment Scale, among others. It should be noted, however, that despite their utility and widespread use in the context of bipolar affective disorder, these measures were not designed to measure specific domains of functional impairment (Martinez-Aran et al., 2007; Bernstein et al., 2016). The WHODAS 2.0 was developed by World Health Organization (WHO) in 1998 to measure two components of International Classification of Functioning (ICF) activity and participation (Cheung et al., 2014). This measure is based on a bio-psychosocial concept of understanding disability and, thus, provides valid, comprehensive, and reliable information on disability and health information systems (Ustun et al., 2010).

The items are selected to represent the ICF's six activity and participation domains: cognition, mobility, self-care, getting along, life activities and participation (Chiu et al., 2014; Federici et al., 2016). The psychometric properties of the WHODAS 2.0 have been analyzed in bipolar affective disorders, demonstrating the reliability and validity of the scores derived from it (Habtamu et al., 2017). WHODAS 2.0 has three versions self rated, proxy rated and interviewer rated. As the Mental Health Care Act, 2017 emphasis on rights perspective and gives importance to the view of service users, hence it is essential to see whether persons with mental illness are able to provide a proper self-assessment of their own disability. Also, by looking at the agreement between the self rated, proxy rated and interviewer rated versions, we may be able to know if these versions can act as proxy measures for the patients whenever they are not able to report their disability themselves thus also protecting their human rights (Kelly, 2016). To the best knowledge of the researcher no study has been conducted in Indian population till now where concordance amongst the self rated, proxy rated and interviewer rated versions of WHODAS 2.0 among the patients of Bipolar affective disorder has been assessed.

## **AIM AND OBJECTIVE**

The present study aimed at assessing the concordance amongst the self, proxy and interviewer administered version of WHODAS 2.0 among the patients with bipolar affective disorder.

## **MATERIALS AND METHODS**

The study was cross sectional in nature. Thirty persons having Bipolar Affective Disorder were selected using a consecutive sampling procedure as per ICD-10 criteria. Researcher using the self, proxy, and interviewer administered versions of WHODAS 2.0 (36 item). The study was conducted at the outpatient department (OPD) of the Mental Health Institute (MHI) and the Department of Psychiatry, Govt. Medical College and Hospital Sector 32, Chandigarh. Person's diagnosed with bipolar affective disorder as per the ICD-10, aged above 18 years of age with a total duration of illness of at least 2 years were included. Those who were refused to give written informed consent for the study were excluded. Caregivers of these patients who were above 18 years of age, any gender, willing to give written informed consent, General Health Questionnaire (GHQ) score less than 3, able to read, write and understand English and has studied up to 10th standard were included in the study.

Ethical clearance was obtained from the Institutional Ethical Committee of GMCH, Chandigarh.

### **Tools used in the study**

**Socio-Demographic Performa and Clinical Data Sheet:** This was a semi-structured proforma that was used to tap details such as age, gender, education level, marital status, type of family, occupation, religion, age of onset of illness, duration of illness, duration of treatment, number of hospitalizations etc.

**The General Health Questionnaire-12 (GHQ-12):** is a well-known and efficient tool for measuring the psychological morbidity in the respondents. It is used worldwide in different segments of practice and research- clinical, epidemiological and psychological. It consists of 12 items with each item measuring the severity of mental health problems in the 4 weeks preceding the study. Scoring method (0-0-1-1) is used to sum up the points to a total score ranging between 0 and 12 with higher score indicating poorer mental health (Goldberg, 1986).

**Capacity Assessment Guidance Document by Government of India:** It is guidance document developed by Government of India, Ministry of Health and Family Welfare as per section 81 (1) of the Mental Healthcare Act, 2017 for assessing, when necessary, the capacity of person to make mental health care or treatment decisions (Government of India, 2019).

**WHODAS 2.0 (36-item Self, Proxy and Interviewer Administered Questionnaire):** The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) 36 item version is an assessment tool developed by the World Health Organization (WHO) to measure disability and functional impairment in accordance with the International Classification of Functioning, Disability and Health. The WHODAS 2.0 measures average functioning in everyday situations for the last 30 days, and surveys six domains of functioning: (1) cognition (understanding and communicating), (2) mobility (ability to move and get around), (3) self-care (e.g., with regard to hygiene, dressing, and eating) (4) getting along with others, (5) life activities (ability to attend to everyday responsibilities), and (6) participation in society (Smith et al., 2010).

**Procedure:** Thirty patients with a diagnosis of Bipolar affective disorder as per the ICD-10 criteria attending outpatient department of Mental Health Institute (MHI), and Department of Psychiatry, Government Medical College and Hospital Sector 32, Chandigarh were approached for the study. For the patient group, first of all, capacity assessment tool was administered. Patients who had capacity, gave written informed consent and fulfilled the selection criteria were included in the study. Patient's group was given WHODAS 2.0 (36 - item version self-administered) to rate their disability and in case they had any queries while filling the questionnaire, they were provided help by the researcher.

The caregivers (proxy) of the same patient were also approached for written informed consent. Those who gave consent and fulfilled inclusion and exclusion criteria were administered socio demographic data sheet and GHQ-12. Caregivers who had a GHQ-12 score equal to or more than 3 were excluded from the study and referred to Psychiatry OPD for further evaluation. The caregivers who scored less than 3 were given WHODAS 2.0 (36-item version proxy administered) to rate their patient's disability. The researcher was

available to help, in case patients or caregivers had any queries regarding filling the questionnaire. Additionally, the researcher also assessed patient's disability independently using WHODAS 2.0 (36-item version interviewer administered). Before administering WHODAS 2.0 scale the researcher was provided extensive training in administration of WHODAS 2.0 by the supervisors.

### **Ethical Consideration**

The purpose and the design of the study was explained to the patient and accompanying primary caregiver in language they understand viz. English, Hindi and Punjabi. The patients were remaining under the treating consultant. No interference was done in the treatment. The patient and the consenting family members were informed that they could withdraw any time from the study without having to give reasons for the same. In any case, they would continue to receive appropriate treatment for their condition. The confidentiality of the information obtained were maintained and was revealed only to doctors/auditors of this study. The defined guidelines of Central Ethics Committee for Biomedical Research on human subjects by ICMR were adhered to, in addition to the principles enunciated in the Declaration of Helsinki.

### **Statistical Analysis**

The data was statistically analyzed. Normality of quantitative data was checked by measures of Kolmogorov Smirnov tests of Normality. Continuous data were reported as Mean  $\pm$  SD. Categorical variables were reported as counts and percentages. All statistical tests were two-sided and performed at a significance level of  $\alpha=.05$ . Analysis was conducted using IBM SPSS STATISTICS (version 23.0).

## **RESULTS**

Table 1 shows the socio demographic characteristics of the Bipolar Affective Disorder patients (N=30). The sample comprised predominantly of males (80.0%). Fifty percent of the sample (50.0%) was in the age range of 40-59 years. Majority of the sample were followers of Hinduism (60.0%). Most of the patients were married (53.3%), were from nuclear family (66.7%) and hailed from rural community (70.0%). Majority of the sample were from union territory of Chandigarh (56.7%) and were comfortable in speaking Hindi language (66.7%).

Table 2 shows the clinical details of the sample. Overall (70%) had a long standing illness of more than 5 years and also taken treatment for illness of greater than 5 years (66.7%). For most of the participants age of onset of illness was in the age group of 18-30 years (50.0%). Majority of the patients neither had any family history of psychiatric illness (96.7%) nor were hospitalized from 1- 5 times in their life time (70%).

Table 3 shows the domain wise inter-rater reliability of WHODAS 2.0 among Bipolar Affective Disorder patients. The overall inter-rater reliability in bipolar affective disorder group came out to be 0.655 (.395-.767) which is indicative of moderate reliability. The domains that had good reliability were cognition (0.898), mobility (0.847) and getting along with people (0.850) whereas domains that exhibited moderate reliability were self -care (0.779), life activities of household (0.748), life activities at school/work (0.558) and participation in society (0.755).

**Table 1: Socio Demographic Profile of Patients (N=30)**

<b>Variables</b>	<b>Description</b>	<b>Percent (N)</b>
<b>Age Group</b>	18-39 Years	36.7 (11)
	40-59 Years	50.0 (15)
	>= 60 Years	13.3 (04)
<b>Gender</b>	Male	80.0 (24)
	Female	20.0 (06)
<b>Marital Status</b>	Single	36.7 (11)
	Married	53.3 (16)
	Widowed	10 (03)
<b>Education</b>	Matric	40.0 (12)
	Intermediate	26.7 (08)
	Graduate	20.0 (06)
	Post-graduate	13.3 (04)
<b>Occupation</b>	Professionals	6.7 (02)
	Technicians and Associate Professionals	16.7 (05)
	Clerks	20.0 (06)
	Skilled Workers and Shop & Market Sales Worker	20.0 (06)
	Skilled Agricultural & Fishery workers	3.3 (01)
	Craft and Related Trade workers	3.3 (01)
	Unemployed	30.0 (09)
<b>Family Income</b>	0 – 10001	26.7 (08)
	10002 – 29972	20.0 (06)
	29973 – 49961	53.3 (16)
<b>Religion</b>	Hinduism	60.0 (18)
	Islam	10.0 (03)
	Sikhism	30.0 (09)
<b>Family type</b>	Nuclear	66.7 (20)
	Joint	33.3 (10)
<b>Locality</b>	Urban	26.7 (08)
	Rural	70.0 (21)
	Others	3.3 (01)
<b>Residence</b>	Punjab	20.0 (06)
	Haryana	10.0 (03)
	Chandigarh	56.7 (17)
	Himachal Pradesh	6.7 (02)
	U.P	3.3 (01)
	Other	3.3 (01)
<b>Language Known</b>	Hindi	66.7 (20)
	Punjabi	33.3 (10)

**Table 2: Clinical Profile of the Bipolar Affective Disorder patients (N=30)**

Variable	Description	Percent (N=30)
<b>Duration of Illness</b>	2-5 Years	30.0 (09)
	6-10 Years	23.3 (07)
	>10 Years	46.7 (14)
<b>Duration of Treatment</b>	2-5 Years	33.3 (10)
	6-10 Years	20.0 (06)
	>10 Years	46.7 (14)
<b>Referred From</b>	Direct	70.0 (21)
	Medical/Surgical and other OPD	6.7 (02)
	Relative	20.0 (06)
	Other	3.3 (01)
<b>Age of onset of Illness</b>	18-30 Years	50.0 (15)
	31-45 Years	36.7 (11)
	46-60 Years	13.3 (04)
<b>Number of Hospitalization</b>	Never	23.3 (07)
	1-5 Times	70.0 (21)
	6-10 Times	3.3 (01)
	16-20 Times	3.3 (01)
<b>Family History of Psychiatric Illness</b>	Yes	3.3 (01)
	No	96.7 (29)

**Table 3: Overall and domain wise Inter-rater reliability of WHODAS 2.0 among Bipolar Affective Disorder Group**

Domain	Inter rater reliability	95% Confidence Interval		Reliability category
		Lower Bound	Upper Bound	
Overall Scale	0.655	.469	.802	Moderate
Cognition	0.898	.813	.948	Good
Mobility	0.847	.721	.922	Good
Self-care	0.779	.592	.888	Moderate
Getting along with people	0.850	.727	.924	Good
Life activities of household	0.748	.544	.871	Moderate
Life activities at school /work	0.558	.181	.777	Moderate
Participation in society	0.755	.482	.884	Moderate

**Table 4: Domain Wise Mean Score for Different Raters in Bipolar Affective Disorder Group**

Domain	Rater category (n=30 in each group)	Mean score	Std. Deviation	95% Confidence Interval		Minimum	Maximum	P-value
				Lower Bound	Upper Bound			
Cognition	Self	3.63	2.6325	.480	2.65	0.0	10.0	.973
	Proxy	3.73	3.1397	.573	2.56	0.0	12.0	
	Interviewer	3.56	2.5822	.471	2.60	0.0	11.0	
Mobility	Self	2.23	1.5906	.290	1.63	0.0	6.0	.641
	Proxy	2.63	1.7317	.316	1.98	0.0	6.0	
	Interviewer	2.40	1.6103	.294	1.79	0.0	5.0	
Self-care	Self	.833	1.7036	.311	.197	0.0	8.0	.90
	Proxy	.867	1.2521	.228	.399	0.0	6.0	
	Interviewer	.833	.9499	.173	.479	0.0	4.0	
Getting along with people	Self	3.63	1.9737	.360	2.89	0.0	8.0	.64
	Proxy	3.83	2.4507	.447	2.91	0.0	9.0	
	Interviewer	4.13	1.6965	.309	3.50	1.0	7.0	
Life activities of household	Self	4.40	2.4858	.453	3.47	0.0	11.0	.19
	Proxy	4.43	2.5008	.456	3.50	1.0	11.0	
	Interviewer	5.46	2.6747	.488	4.46	1.0	12.0	
Life activities at school/work	Self	.633	1.6078	.293	.033	0.0	8.0	.92
	Proxy	.767	1.5906	.290	.173	0.0	6.0	
	Interviewer	.633	1.3257	.242	.138	0.0	6.0	
Participation in society	Self	8.50	2.3889	.436	7.60	4.0	13.0	.003*
	Proxy	8.96	2.7728	.506	7.93	4.0	15.0	
	Interviewer	10.7	2.5617	.467	9.74	6.0	16.0	

\*\*P&lt;0.01

Table 4 shows the significant difference in Bipolar Affective Disorder group (P<0.003) in the rating done by self (patient) and proxy (caregiver) as compared to interviewer (clinician) rating in 'participation in society' domain and rest all domains did not show any significant difference.

## DISCUSSION

The WHODAS 2.0 has suitable psychometric properties in terms of reliability and validity when applied to patients with bipolar affective disorder. The present study checked the concordance among the three versions; self, proxy and interviewer on the 36-item WHODAS 2.0 based on a sample of 30 patients with bipolar affective disorders (Aslan-Kunt & Dereboy 2018). The overall inter-rater reliability among self, proxy and interviewer rated version of WHODAS 2.0 in bipolar affective disorder group came out to be 0.655 (.395-.767) indicative of moderate reliability. The domains that had good reliability were cognition (0.898),

mobility (0.847) and getting along with people (0.850) whereas domains that exhibited moderate reliability were self-care (0.779), life activities of household (0.748), life activities at school/work (0.558) and participation in society (0.755). The findings are similar to one of the previous studies where results indicated moderate reliability among the two domains of WHODAS 2.0 36-item version (Aslan-Kunt & Dereboy 2018).

Also, there was no significant difference among the self, proxy and interviewer assessment for most items on WHODAS 2.0. However significant difference ( $P < 0.003$ ) was seen in the domain of 'participation in society', wherein the self and proxy who were administered WHODAS 2.0 gave lesser score respectively as compared to interviewer. The 'participation in society' domain addresses that the patient's feelings about society's view of their disease as well as the impact of their illness on their families. The evidence is suggestive that stigma impacts not only the patients suffering from mental illness, but also on people who are closely related to them like family, friends and relatives (Jain et al., 2016).

Bipolar affective disorder has received much attention in stigma and it is one of the most disabling and stigmatizing of mental illness (Guilera et al., 2015). They continue to face stigma, social exclusion, discrimination, and violation of their human rights in the country. This is mainly due to the myths, misconceptions and cultural beliefs associated with mental illness. They are robbed of opportunities for quality of life and purposeful interaction in their communities, with family members and friends. Participation is regarded as crucial to a person's well-being and quality of life (Gspandl et al., 2018). Majority of the participants in the present study were from the rural background where mental illness is still stigmatized, and such persons were perceived differently by the society. This may be the reason for high scores in the clinician rated version of WHODAS 2.0 in the domain of 'participation in society. These findings are comparable to another study by (Jain et al., 2016). Where they highlighted that stigmatization is higher in rural areas. In the present study, participation domain was most closely related to symptoms of severe mental illness.

The less participation in society could be due to important factors closely linked to bipolar affective disorder i.e., unemployment and stigma. Unemployed participants are less capable than others of participating in community activities. Due to chronic nature of illness most patients with bipolar affective disorder fail to return to their pre-morbid level of functioning, thus becoming chronically unemployed (Chen et al., 2017). The stigma of bipolar affective disorder is another cause of the patient's limited employment opportunities and it is more prevalent in Asian countries than Western ones. Persons with a severe mental illness have lack of insight and cognitive impairment (Kim et al., 2010).

The results of the present study i.e., to see the concordance amongst the self, proxy and interviewer versions are pertinent with Mental Health Care Act, 2017 perspective as patient has the capacity to assess his or her disability using the self-administered version. As per the Mental Health Care Act 2017, it is mentioned that there is a right of the patient in the form of advance directives and also to choose the treatment facilities. Clinical rating typically assesses disability and activity restriction. It gives information regarding specific behavior observed and is less vulnerable to psycho-social influences, but it is restricted in that a small sample of seen behavior may result in an underestimation of a patient's capacity.

### **Strength and Limitations of the study:**

This study had many strengths like only clinically stable patients were induced in the study, stringent inclusion and exclusion criteria were followed, all ethical considerations were well taken care of and what made it unique is that, to the best knowledge of the researcher it is the first such study in India that checked the concordance amongst the self-rated, proxy rated



and interviewer rated versions of World Health Organization Disability Assessment Schedule (WHODAS) 2.0 36- item Version among the patients of bipolar affective disorder. However certain limitations were also identified like small sample size, potential bias cannot be ruled out as the rater was not blinded to the diagnosis of the participants and finally, the study participants were restricted to specific diagnosis viz. bipolar affective disorder who visited a clinical facility which could limit the generalization of the result.

## CONCLUSION

Thus, it can be concluded that overall inter rater-reliability of WHODAS 2.0 among the self, proxy and interviewer versions was moderate with no significant difference among the self, proxy and interviewer assessments for most items. This upholds the principle of advance directives as articulated by MHCA, 2017 that gives right to persons with mentally ill having capacity to take treatment related decisions, thereby increasing the self-reliance of the patient and their caregivers in access to healthcare. Finally, it is suggested that similar studies needs to be conducted with a larger sample size to generalize the present study findings. Also, disability due to the other mental illnesses needs to be investigate using the similar tools to identify concordances among all the three versions of WHODAS 2.0.

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**Ethical Clearance:** The study protocol was reviewed and approved by the Ethics Committee of the GMCH Chandigarh sector 32.

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