Research Report

A CROSS-SECTIONAL STUDY OF PERCEIVED HUMAN RIGHTS IN MENTALLY ILL

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ABSTRACT

Background: People with mental illness may experience wide range of human rights violations. Quantifying perceived human rights in mentally ill and putting it into perspective will help to systematically identify areas for intervention and to monitor their effectiveness.
Objectives: To compare perceived human rights in persons with mental illness to a group of individuals without mental illness, and to assess if the perceived human rights have any relationship with sociodemographic variables.
Methods: Data were collected from two groups: the first group comprised of 72 mentally ill persons (MI group) attending the community mental health clinics of Kannur district in the Indian state of Kerala, and the second group comprised of 72 individuals without mental illness (Non-MI group) who were visitors to patients in a government hospital. A comparative, cross sectional design was used. A demographic proforma tool, Human Rights Questionnaire (HR-14), and HR–Work supplementary tool (HR-Work) were used to collect information.
Results: MI group reported significant deficits in overall fulfillment of perceived human rights, specifically in the in the interindividual and work domains. Significant deficits were also detected in certain items related to health care and community in the MI group.
Conclusion: Mentally ill perceive considerable deficits in the fulfillment of human rights in various areas. These findings are relevant in many respects.

Key words: Perceived human rights, mental illness

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INTRODUCTION

Mental disorders represent four of the ten leading causes of disability worldwide.[1] People with mental illness may be experiencing a wide range of human rights violations.[2] Majority of the mentally ill may be excluded from community life and denied basic rights such as shelter, food and clothing; and this could be due to stigma and misconceptions associated with mental illness.[3] Mentally ill are also discriminated against in the fields of employment, education and housing.[4] Very few studies have been done on perceived human rights and its correlates among mentally ill in India. Most previous studies were limited to the qualitative domain, and hence may lack objectivity and rigor.[5] Quantitative studies would help overcome such limitations and would help improve the attitudes of both the professionals and the public.

Perceived human rights: In this study, "perceived human rights" refers to the fundamental rights perceived by a person in terms of four underlying principles of international human rights legislation: dignity, participation, equity, and justice; and three levels of interactions: with another individual, with societal bodies like the civil administration, and with the health care system; as measured by Human Rights Questionnaire (HR-14) and HR-work supplementary module (H-Work).[6]

Objectives of the study: The purpose of this study was to assess the perceived human rights of people with mental illness (MI) and to compare them with individuals without mental illness (Non-MI). The study also aimed to look for relationships between perceived human rights and selected demographic variables in the MI group.

METHODS AND MATERIALS

This was a cross-sectional study that used purposive sampling technique. Data were collected by the principal investigator using the interview method in January 2009. The study was not funded by any external agency, and has no conflicts of interests. The data sheet included demographic variables and relevant tools. Theoretical model for this study was developed using the concepts of Wildner on health and human rights, and dynamic interacting systems explained by King.[4,7]

Sample: "People with mental illness" (MI) refers to persons diagnosed to have either schizophrenia or bipolar disorders in remission/recovery as per the Tenth Revision of International Classification of Diseases, Diagnostic Criteria for Research (ICD-10 DCR) by their treating psychiatrist, and have insight about their illness.[8] These two disorders were selected because people affected by them are more likely to experience stigma and discrimination than those with depression or anxiety disorders. "Individuals without mental illness" (Non-MI) refer to those found to be free from any major psychiatric or medical illness after getting a score below two on the 5-item General Health Questionnaire (GHQ-5).[9]

Sample size calculation: We reviewed qualitative literature in the field of human rights in mental health, and adopted Cohen's convention of a medium effect size (0.5) for this study.[10,11] So, with an effect size of 0.5, α of < 0.05 and β of 0.80, the required sample size was approximately 64 in each group.

Tools: The Human Rights Questionnaire (HR-14) has 14 items which measure the fundamental rights perceived by a person in terms of four underlying principles of international human rights legislation and

three levels of interaction.[6] The scale covers three domains: interindividual, health care and community; and is scaled with a seven-point Likert-scale ranging from zero to six. We also used an additional scale for workplace setting (HR-work) to complement the first tool so that those who are not working, like unemployed or retired persons, too can be assessed. The Human Rights-Work Supplementary (HR-Work) has five items, and measures work-related human rights areas like dignity (colleagues), dignity (supervisors), participation, justice, and equity.[6] Psychometric properties of these questionnaires have been established by previous studies, and they are found to have adequate construct validity, test-retest reliability (ICC = 0.69) and internal consistency (Cronbach's alpha = 0.76).[6,12]

Permission was obtained from the authors of these tools for their use in this study. We translated the tools to Malayalam, and language validity was established by back translation and comparison.[13] Content validity was established by obtaining approval from seven experts in various disciplines related to mental health. Results were recalculated as percent fulfilment, with six points corresponding to 100% fulfillment.

Ethical aspects: As the study was undertaken as a part of academic project of the principal investigator, ethical approval was obtained from the Institutional Ethics Committee of College of Nursing, Manipal University, in 2009. Permission was also obtained the Program officer of District Mental Health Program (DMHP), Kannur, Kerala. Written informed consent was obtained from the participants, and voluntary nature of the study was explained.

Analysis: SPSS software package (Version 11.5 for windows) was used for analysis. Descriptive and inferential statistics were used. Demographic characteristics of two groups were compared using the Chi-square test. As the data were not normally distributed, Mann - Whitney U test was used for comparing the human rights scores of the two groups. Association between HR-14 and demographic variables of the MI group was analyzed using appropriate parametric tests.

RESULTS

Details of the two groups: To the MI group, we recruited 72 patients who attended 15 community mental health clinics in Kannur district of Kerala. To the Non-MI group of 72 individuals without mental illness, we recruited those visiting non-psychiatric patients admitted in a government hospital of the same district. Of those approached, less than 10 persons refused to participate due to their time constraints.

The two groups were comparable on age group, gender, religion and education. However, there were statistically significant differences between the groups on occupation type, socio-economic status (SES), marital status, and family type. MI group included two subgroups: schizophrenia in remission (n=32; 44.4%) and bipolar disorder in remission (n=40; 55.6%) (Table 1).

Perceived Human Rights: The MI group had significantly lower overall score (HR-14 Sum) (p=0.001) (Table 2). HR-Interindividual domain subscale showed significantly lower score in MI group (p=0.001) (Table 2). No significant intergroup differences were noticed in the HR-Health Care domain subscale (p=0.49)

or the HR-Community domain subscale (p=0.22). When the HR-Interindividual domain items were compared, the MI group showed significant low score on items from family and friends on areas of dignity

Demographic Variables	MI group (n=72)		Non-MI group (n=72)		χ^2	p value
	F	%	F	%		
Age					3.36	**0.34**
21-30 years	10	13.9	16	22.2		
31-40 years	27	37.5	26	36.1		
41-50 years	24	33.3	16	22.2		
Above 50 years	11	15.3	14	19.4		
Gender					0.852	**0.36**
Male	54	75.0	49	68.1		
Female	18	25.0	23	31.9		
Religion					1.838	**0.40**
Hindu	47	65.3	54	75.0		
Muslim	17	23.6	11	15.3		
Christian	8	11.1	7	9.7		
Education					3.944	**0.27**
Primary	15	20.8	13	18.1		
Secondary	39	54.2	33	45.8		
Higher secondary	14	19.4	15	20.8		
Graduation	4	5.6	11	15.3		
Type of Family					4.267	**0.04**
Nuclear	39	54.2	51	70.8		
Extended	33	45.8	21	29.2		
Marital Status					23.976	**0.01**
Single	30	41.7	8	11.1		
Married	36	50.0	63	87.5		
Separated/Widowed/ Divorced	5	8.4	1	1.4		
Occupation					6.96	**0.03**
Unemployed	18	25.0	22	30.6		
Unskilled	40	55.6	25	34.7		
Skilled	14	19.4	25	34.7		
Socioeconomic Status					10.48	**0.001**
BPL	53	73.6	34	47.2		
APL	19	26.4	38	52.8		
Diagnosis						
Schizophrenia	32	44.4	--	--	-	-
BPAD in remission	40	55.6	--	--		

Table 1: *Distribution of sample characteristics: Comparison between MI group and Non-MI group (n=144)*

Perceived Human Rights: Sub-scales and Overall score	MI group (n=72)		Non-MI group (n=72)		Z-Score	p value
	Median	Inter quartile range	Median	Inter quartile range		
HR-14 Sum	72.02	25.22	83.92	19.94	3.85	**0.001**
HR-Interindividual	68.05	27.77	88.88	16.66	6.71	**0.001**
HR-Health Care	79.16	23.95	83.33	28.12	0.7	**0.49**
HR- Community	66.87	33.33	75	29.17	1.23	**0.22**

Table 2: *Comparison of Perceived Human Rights- Overall score and Sub-scales between MI and Non-MI groups: Mann-Whitney U Test (n = 144)*

(p=0.003), participation (p=0.001), equity (p=0.001), and justice (p=0.001); and items from other people on areas of justice (p=0.001) and equity (p<0.001).

In the HR-Health Care domain, significantly low scores were found in areas of equity (p<.001) and justice (p=0.031) in the MI group. On the other hand, scores for the items of participation and dignity were comparable. Comparison of HR-Community domain items revealed significantly lower scores in areas of equity (p=0.002) and justice (p=0.002). Significant differences were not present on items of participation and dignity (Table 3).

Work-related Perceived Human Rights: Significantly low scores were reported in MI group (p<.001) on overall work-related perceived human rights (HR-Work Sum) (Table 4). HR-Work items in dignity from colleagues (p=0.016), participation (p=0.001), justice (p=0.046) and equity (p=0.001) too showed significantly low scores in the MI group. The groups were comparable on dignity from supervisors (Table 4).

Relationship between perceived human rights and demographic variables in the MI group: We also analyzed if there is any relationship between perceived human rights and any sociodemographic variables of the MI group like gender, SES, family type, occupation, marital status and religion. Significant difference was found between mean HR-14 Sum score and different categories of family type (p=0.005), as shown by a better perception of human rights among MI group from nuclear families when compared to extended or joint families. Similarly, there was significant difference between mean HR-14 Sum score and different marital status categories (p<.001) as shown by a higher score in married participants, than in unmarried participants and in Widowed/Divorced/ Separated participants. However, overall perceived human rights were independent of variables like gender, socioeconomic status, occupation and religion (Table 5).

DISCUSSION

Demographic Variables: In this study, though the two groups were comparable on age group, gender, religion and education; there were marginal differences between the two groups on the variables occupation and

Perceived Human Rights	MI group (n=72)		Non-MI group (n=72)		Z-Score	p value
	Median	Inter quartile range	Median	Inter quartile range		
Interindividual- Dignity (Family and Friends)	83.33	50	100	33.33	3.02	**0.003**
Interindividual- Participation (Family and Friends)	66.66	66.66	100	0	6.46	**0.001**
Interindividual- Equity (Family and Friends)	83.33	33.33	100	0	5.6	**0.001**
Interindividual- Justice (Family and Friends)	50	50	100	33.33	4.73	**0.001**
Interindividual- Justice (Other People)	50	50	83.33	33.33	4.68	**0.001**
Interindividual- Equity (Other People)	83.33	50	100	0	6	**0.001**
Health Care - Equity	83.33	45.83	100	0	5.27	**0.001**
Health Care - Justice	83.33	50	100	33.33	2.15	**0.031**
Health Care - Participation	100	33.33	83.33	50	1.8	**0.070**
Health Care - Dignity	83.33	33.33	83.33	50	1.38	**0.169**
Community - Participation	66.66	66.66	66.66	83.33	0.57	**0.567**
Community – Equity	100	29.166	100	0	3.14	**0.002**
Community – Justice	59.17	33.33	83.33	33.33	3.06	**0.002**
Community – Dignity	83.33	50	83.33	66.66	0.31	**0.755**

Table 3: *Comparison of Perceived Human Rights -Items between MI group and Non-MI group-Mann-Whitney U-Test (n=144)*

Perceived Human Rights	MI group (n=54)		Non-MI group (n=50)		Z-Score	p value
	Median	Inter quartile range	Median	Inter quartile range		
HR -Work Sum	81.66	25	93	20.9	3.34	**0.001**
Work -dignity (Colleagues)	83.33	41.66	100	16.66	2.4	**0.016**
Work - dignity (supervisors)	83.33	50	100	16.67	0.89	**0.375**
Work – participation	66.67	45.83	83.33	16.67	3.2	**0.001**
Work – justice	66.67	50	100	33.33	2	**0.046**
Work – equity	83.33	41.67	100	37.5	4.44	**0.001**

Table 4: *Comparison of work-related perceived human rights between MI group and Non-MI group: Mann-Whitney U Test (n=54*+50*=104) *People who were employed.*

Variable		n	HR-14 Sum Score		Test statistic	p value
			Mean	S.D		
Gender	Male	54	72.05	17.5	t-test	**0.235**
	Female	18	66.53	14.91	1.198	
SES	BPL	53	69.91	17.46	t-test	**0.52**
	APL	19	72.81	15.86	0.63	
Family Type	Nuclear	39	75.74	16.07	t-test	**0.005**
	Extended	33	64.69	16.29	2.88	
Occupation	Unemployed	18	64.21	15.1	ANOVA	**0.17**
	Unskilled	40	72.54	16.66	1.79	
	Skilled	14	73.65	19.19		
Marital Status	Single	30	64.14	16.94	ANOVA	**<.001**
	Married	36	78.18	14.49	8.94	
	Widowed/Divorced/ Separated	6	58.35	11.05		
Religion	Hindu	47	69.61	18.12	ANOVA	**0.479**
	Muslim	17	70.38	13.16	0.744	
	Christian	8	77.55	17.66		

Table 5: *Relationship of Perceived Human Rights and Selected Demographic Variables in MI group (n=72)*

family type. A previous study has also reported similar results.[14] When marital status was compared, the two groups were significantly different — with a higher number of married persons in Non-MI group (87%) than the MI group (50%). This should be read in the context that epidemiological studies have consistently found high unmarried status among people with serious mental illness. This may be because the mental illness lessens the chances of marriage and increases the chance of divorce.[15] Considering socioeconomic status (SES), a high number of participants (74%) in the MI group belonged to BPL (Below Poverty Line) category, an economic benchmark and poverty threshold used by the government of Kerala.[16] On the other hand, majority (53%) in the Non-MI group belonged to APL (Above Poverty Line) category. A previous study too had reported such a relationship between SES and mental illness.[17]

Perceived human rights and mental illness: Comparison of the scores for perceived human rights on the full score of 100 revealed significant deficits in fulfillment of overall perceived human rights in the MI group. Similar findings have been reported by a previous study in which majority of the participants reported feeling apprehensive that others would avoid them due to their mental illness, and most frequently in the domain of interpersonal interaction.[18]

On the interindividual domain, significant infringements were reported by our MI group on areas of dignity, participation, equity, justice from family and friends, as well as justice and equity from other people. A previous multicenter study had reported similar results of discrimination experienced by people with mental illness.[19] Negative discrimination was experienced by most of their participants (47%) in making or keeping friends, from family members, in finding a job, in keeping a job, and in intimate or sexual relationships. That study

also reported anticipated discrimination among majority of the participants (64%) in applying for work, training, or education; and in looking for a close relationship. Majority in that study also experienced their diagnosis as labeling[19]. These findings are consistent with our own findings.

In contrast to the earlier reported evidence, this study did not find any significant difference between the two groups on overall health care related human rights.[20] But the MI group reported significant deficits in some items within this domain like equity and justice. There were no significant differences in the areas of participation or dignity. From this, we may assume that human rights violations are less severe in community mental health care settings in India compared to the situation abroad. It may also be concluded that mentally ill may not be experiencing much human rights violations from health care workers. However, this finding cannot be generalized to more restrictive facilities like mental hospitals. These findings should also be read in the context of a qualitative study done in a developed country which examined the experience of persons recovering from serious and persistent mental illness, and highlighted the need for patients to be active participants in their care so as to develop independence and sense of self.[21]

Similarly, this study did not find any significant difference in fulfillment of community related human rights. However, HR-Community domain items showed significantly low scores on areas of equity and justice. But no significant differences were found in the areas of participation or dignity. In a previous study on perceptions of discrimination among persons with serious mental illness in a developed country, more than half of the participants had reported some experience with discrimination, mostly in occupation, housing, and from legal system.[14]

In our study, the MI group reported significantly low overall work-related human rights, as well as low scores in dignity from colleagues, participation, justice, and equity. The groups were comparable on dignity from supervisors. These findings are consistent with previous studies highlighting discrimination faced by the mentally ill at work place and in getting employment.[22,23]

Our results indicate considerable deficits in the fulfillment of human rights in various areas among the mentally ill. Measurement of perceived fulfillment of human rights helps to identify deficits within societies and also across societies. In this study, two groups were compared, one of them being more likely to be subjected to different kinds of human rights violation. These results are relevant in many respects: They suggest that there is an imperative need to take necessary steps to defend, promote, and fulfill human rights of people with mental illness through education of the public and interventions targeting close relatives and health care personnel. Quantifying perceived human rights status and putting it into perspective will help to scientifically identify areas for action and to monitor progress.

The limitations of this study include the use of purposive sampling technique and the use of a questionnaire which was relatively brief to cover the broad field of human rights.

CONCLUSION

This study shows that mentally ill persons perceive significantly lower human rights in comparison to those without mental illness from similar socioeconomic and cultural background. On the interindividual domain, deficits were seen in all areas — dignity, participation from family and friends, and equity and justice from family

and friends as well as other people. In the health care domain, significant deficits were seen in the areas of justice and equity. Overall health related human rights scores were comparable. In the community domain, there were significantly low scores in equity and justice. There was no difference between the scores obtained by the two groups in the overall community domain score. On the work-related human rights domain, significant deficits were reported on overall score and items on dignity from colleagues, participation, justice, and equity. The differences in the socioeconomic, marital and employment status of the two groups may have influenced these results, and that aspect needs to be investigated in future research.

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