

Chapter 6

Understanding Psychological Distress Among Female Caregivers of the Patients With Mental Illness

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ABSTRACT

The present study aims to find the level of psychological distress in female caregivers of patients with mental illness in the context of Jharkhand and its relations with the socio-demographic variable. The sample was drawn from five blocks of Hazaribagh districts of Jharkhand and the respondents were 200 relatives of the patients with mental illness. A socio-demographic data sheet used for recording the socio-demographic characteristics and Kessler Psychological Distress Scale version 10 (K10) used for assessing their psychological distress. The result shows that female gender is having more psychological distress than male and may lead to common mental disorder under persistent condition. The mean score of female was higher than male (i.e., 26.36 [SD= 9.44] and 22.23 [SD= 8.86], respectively). The difference between both the genders found to be significant at less than 0.001 p values in Man Whitney U test.

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*Understanding Psychological Distress Among Female Caregivers***INTRODUCTION**

Psychological distress which encompasses of worthlessness, hopelessness, sadness leads to gradual loss of interest to socialize and to work triggered by unfriendly socio, economic and cultural environment (Mirowsky & Rose, 2002; Kleinman, 199; Kirmayer, 1989). This didn't stop only to emotional disturbance but can cause to neurotic and mental disorder in the absence of proper support (Phillips, 2009; Watson, 2009). Relatives or the caregiver of the patients with mental or physical illness are not spared of its influences. Relatives or caregivers staying with their patients live in the same social, cultural and economic environment exhibit tremendous stress due to handling the symptoms of patient with financial insufficiency and stigmatized attitude of the society with less cooperation from the neighbors (Eag, 2014; Lesselo, Kajula & Malema, 2016; Raj, Shiri & Jangam, 2016; Chadda, 2014). In such environment, women who look after the family members, kids and old parents get additional workload to look after her man who has met with mental illness who was earlier the bread earner of the family. The noncooperation of other members of the family, expressed emotion of the other member on her husband, critical comments by in laws, physical abuse, domestic violence done by irresponsible alcoholic and substance abused husband, guilt of not able to sustain financially, concern of the suicidal behavior of the patient, over load of roles and responsibilities towards the family, recapitulation of the memories of the leisure and its gradual decrease in frequency and poor physical health in addition to the earning pressure mounting on the shoulder of the women can put her under the high level of psychological distress leading her to suffer from common to severe mental disorder (Ramiro, Hassan, Peedicayil, 2004; Vizcarra et al., 2004; Kingston, McDonald, Austin, Tough, 2015; Jungbauer et al., 2004). Therefore, bringing the symptoms into the notice and their management seems necessary (Kessler et al., 2003). Being one of the least developed states of India, Jharkhand has very poor health facilities. Adequate medical facilities are mostly confined to capital and other important towns. Underutilization of medical care and naxalite activities which sometimes corners transportation and reluctant attitude of medical staff to move into the remote rural areas and cultural practices and unawareness of medical schemes among local residents make the existing scenario more complicated (Saxena, 2009; Statistical Profile, 2013; Gosh, 2014). There are few studies on prevalence and comparison of psychological distress and its correlates exist in India and hardly any studies is there which talk about psychological distress of caregivers of mentally ill patients and especially the comparison among gender.

Therefore, the present study is trying to find out the distress level among gender with the significant association with education, occupation and income.

*Understanding Psychological Distress Among Female Caregivers***METHODOLOGY**

The current study is a community based cross-sectional study conducted at Hazaribagh district between July 2014 and February 2016. The study cover 200 individuals living with mental illness. The sample size was calculated on the basis of population of adult i.e. 12 lacks in Hazariagh district (mention the State) with an expected 20% prevalence of mental illness as reported by the previous studies with an 95% confidence level and 0.05 confidence interval ^[18–20]. Respondents were either had blood relations or marriage, living for more than 2 years were included in the study. Any person having physical or mental retardation, illness or age below 18 years and above 60 years has been excluded from the study. Nav Bharat Jagriti Kendra (NBJK), a nonprofit organization serving community with psychiatric program in Hazaribagh District extending their support by providing the lists of 1200 patients with mental illness which facilitated to find out the relatives of mentally ill patients. To strictly follow the inclusion and exclusion criteria, the study used purposive sampling technique. The data was collected door to door and informed written consent was taken from respondents. A semi- structured socio-demographic data sheet was used to record socio- demographic details of the respondents. To collect distress score, Kessler Psychological Distress Scale (KPDS) version 10 was used. This scale is consists of 10 questions with emotional responses ranging to 5 different levels for each questions from “none of the time” to “all the time”. The score ranges between 10 and 50. Lower score indicate “nil, mild, moderate” and higher score meant “severe” distress. The 2001 Victorian Population Health Sur-vey adopted a set of cut off scores which guided to screen Distress level, a score between 10-19 means ‘likely to be well’, 20-24 ‘likely to have a mild disorder’, 25-29 ‘likely to have a moderate disorder’ and 30-50 indicated ‘severe dis-order’ (Victorian Population Health Survey, 2001). The scale was in English, therefore, who were unable to read or comprehend were assisted by the train volunteers consist of post graduate students. Frequency and percentiles were used for comparing socio-demographic variables; Man Whitney U test was used for comparing distress among genders.

RESULTS

The table 1 shows the presence of psychological distress among gender at different levels. The table clearly shows that females are less “likely to be well” i.e. 28.1% than male who accounts to 46.2% in this category. Females have been reported to develop “severe disorder” i.e. 40.6% al-most half of the population falls under this category whereas figures for male for the same category accounts to 20.2% only. The difference in distress score among gender has been found statistically significant

Understanding Psychological Distress Among Female Caregivers

Table 1. Showing the presence and comparison of psychological distress among the Gender (N=200)

Group	Likely to be well n(%)	Likely to have a mild disorder n(%)	Likely to have a moderate disorder n(%)	Likely to have a severe disorder n(%)	Mean score±SD	Mann Whitney U	P
Male	48(46.2)	21(20.2)	14(13.5)	21(20.2)	22.23±8.86	3680.000	0.001***
Female	27(28.1)	14(14.6)	16(16.7)	39(40.6)	26.36±9.44		

Note- ***significant at 0.001 level.

Table 2. Socio demographic profile of male and female (N=200)

Variable		Male=104/ (%)	Female=96/ (%)
Educational status	Illiterate	5 (4.8)	36 (37.5)
	Below 10 th	39 (37.5)	43 (44.8)
	10 th pass	21 (20.2)	10 (10.4)
	Intermediate	16 (15.4)	4 (4.2)
	Graduate and above	23 (22.1)	3 (3.1)
Occupational status	Unemployed	12 (11.5)	55 (57.3)
	Daily wagers	27 (26.0)	16 (16.7)
	Farmers/ self-employed	34 (32.7)	15 (15.6)
	Govt./Private Jobs	31 (29.8)	10 (10.4)
Income in Indian rupees (Annually)	Less than 25000	17 (16.3)	58 (60.4)
	25000 to 1 lakh	61 (58.7)	28 (29.2)
	1 lakh and above	26 (25.0)	10 (10.4)

at p- value less than 0.001 levels in Mann Whitney U Test.*Table 1. Showing the presence and comparison of psychological distress among the Gender (N=200)*

The table 2 talks about the socio- demographic variable of genders, where in terms of education, there has been a significant difference in education level where majority of respondents are having low level of education but high number of women are illiterate and below matriculation of education i.e. 37.5% and 44.8% whereas in male, despite high number of middle school educated i.e. 37.5% still there are significant number of males in graduation category 22.1%. When it comes to occupation, male population show significant participation in daily wagers, farmers or self-employed and professional or regular jobs i.e. 26% 32.7% and 29.8%. But figures in female show totally opposite picture where 57.3% of females are unemployed, 16.7% are daily wagers, 15.6% are farmers/self- employed and 10.4% are professional or in regular

Understanding Psychological Distress Among Female Caregivers

jobs. Due to this, income also varies in both the group where significant population of male lies between 25,000 to 1 lakh and above i.e. 58.7% and 25% respectively. In female, significant number of women earns below 25,000 rupees annually i.e. 60.4% and moderate amount of women lies between 25000 and 1 lakh i.e. 29.2% and only 10.4% of the female income is above 1 lakh category. The difference in all categories has been found significant in chi-square test at 0.001 levels.

DISCUSSION

The finding of the study presents the prevalence of mild to severe psychological distress. Despite male population of 46.2% are “well”. Still, aggregate percentage of male population is between “mild to severe” distresses in which 20.2% falls in “severe” categories. In female, 28.1% of female are “well” but aggregate of female population 71.9% lies between “mild to severe” categories. It is important to note that half of the male respondents are well and majority of female are in distress. The current study used Kessler Psychological Distress scale for measuring psychological distress. The scale has wide acclamation and acceptance across globe to identify Common Mental Disorder (CMD) with minimum biases and high reliability validity. Higher score indicate presence of mental illness (Baillie, 2005).

Relatives suffer from Common Mental Disorder (CMD) which deepens their distress level. They feel mental illness has brought disgrace to the family in short, stigma of being a relative of mentally ill. Subjective and objective burden, social discrimination by society concertize the “taboo” (Hoening & Hamilton, 1966; Cousineau, McDowell, Hotz, & Hebert, 2003; Ptaznik & Nelson, 1984). Being in the early adulthood and lacking experience of handling the patient increases the distress level causes expressed emotion, quarrel leading to unhealthy relationship between patient and his/her caregiver (Kumar et al., 2009; Lazzarino et al., 2014; Liebanapressa et al., 2014; Link & Phelan, 2001; Magana, et al., 2007; Martin, 1992).

Female as per the current study has more psychological distress which has been corroborated with the other studies (Natalie, Ian, Steve, & Paul, 2003; Math & Srinivasanraju, 2010; Mirowsky & Ross, 2002). Female, especially the spouse has to look after the family members, her morbid husband and has to earn for the sustenance of the self and other members of the family resulting in greater distress, burden and strain on health (Natalie, et al., 2003; Nwanze, 2011; Ostman, & Kjelin, 2002; Perlick et al., 1999; Phillips, 2009; Pits, & Sansen, 2015). However several studies contradicted with the argument and didn't find differences in stress and burden among genders (Prasad, Abraham, Akila, Joseph, & Jacob, 2003; Ptaznik & Nelson, 1984; Ramiro, Hassan, & Peedicayil, 2004; Rautkis, Koeske, & Tereshko, 2004).

Understanding Psychological Distress Among Female Caregivers

The association of socio-demographic factors gives the complete picture of differences in distress level. As per the figures, women are more illiterate and under educated as comparison to males which supports the facts of ignorance and poor understanding of mental illness, sluggish coping skills, more expressed emotion, domestic violence, burnout and fear of any step leading to injury or death of the patient. Often these women are mostly engaged in low paid jobs and most of the time unemployed and take substantial risk in jobs which results in illness, injury and spending on treatment thus, low saving and low income. So the mounting distress and burden confirms the presence of unidentifiable disorder (Reinares et al., 2006; Sakuma et al., 2015; Sanuade&Boatema, 2015).

Males as per study are under educated and moderately lies in matriculation, intermediate and graduate category and fairly distributed across different categories of occupation and relatively have better income level than female and hence have less psychological distress. Studies indicated males having “managerial style” help them to stay away with patients leading to less stressful situation by disseminating task (Saxena, 2009). Therefore, many studies across continents have proved lower education, low paid & uncertain occupation and low income are associated positively with psycho-logical distress irrespective of gender (Schulz & Williamson, 1991; Shah, Wadoo & Latoo, 2010; Sharma, Chakraborti, & Grover, 2016; Sintayehu et al., 2015; Sreeja, Sandhya, Rakesh & Singh, 2009; Vijayalakshmi et al., 2013).

It is interesting to note that socio- economic indicator has given the perfect clue to researchers and policy-makers exactly where to intervene. Jharkhand where basic infrastructure is sluggish is needed to improve. Proper educational and primary health facilities need revision and so as psycho-education is needed across community and gender to improve mental health of both patient and relative. Strategies are required to empower women by providing training on different trades, to make them social entrepreneur and independent and financial aids to the women and family of the mentally ill should be incorporated by the policymakers through different social schemes (Vizcarra et al., 2004; Waris & Viraktamath, 2013; Watson, 2009; Yusuf & Nuha, 2011; Zendjidan et al., 2012).

CONCLUSION

Due to small sample size and purposive sampling technique without incorporating all the districts of Jharkhand it is hard to generalize the study. So it would be beneficial for the researchers and policymakers if they replicate the same for the entire Jharkhand and plan policy accordingly. The study despite limitations is able to reveal the unidentified psychological disorder the relatives of patient with mental illness are facing, vulnerability of women of being caregiver of the mentally ill and

Understanding Psychological Distress Among Female Caregivers*Table 3. Difference in distress level along with socio- demographic variable between two group (N=200)*

Variable	Group	Category	Well	Mild	Moderate	Severe	Total	Chi-square	P value
Education	Male	Below 10 th	14(35.9)	6(15.4)	6(15.4)	13(33.3)	39(100)	20.016	.067
		10 th Pass	10(47.6)	6(28.6)	3(14.3)	02(09.5)	21(100)		
		Intermediate	13(81.2)	1(06.2)	0(00.0)	02(12.5)	16(100)		
		Graduate	10(43.5)	7(30.4)	4(17.4)	02(08.7)	23(100)		
		Illiterate	01(20.0)	1(20.0)	1(20.0)	02(40.0)	05(100)		
	Female	Below 10 th	14(32.6)	11(25.6)	05(11.6)	13(30.2)	43(100)	32.017	.001***
		10 th Pass	05(50.0)	01(10.0)	02(20.6)	02(20.0)	10(100)		
		Intermediate	03(75.0)	00(00.0)	00(00.0)	01(25.0)	04(100)		
		Graduate	02(66.7)	01(33.3)	00(00.0)	00(00.0)	03(100)		
		Illiterate	03(08.3)	01(02.8)	09(25.0)	23(63.9)	36(100)		
Occupation	Male	Unemployed	05(41.7)	03(25.0)	02(16.7)	02(16.7)	12(100)	4.565	.870
		Daily wager	13(48.1)	06(22.2)	04(14.8)	04(14.8)	27(100)		
		Farmer & self	19(55.9)	04(11.8)	04(11.8)	07(20.6)	34(100)		
		Employed	11(35.5)	08(25.8)	04(12.9)	08(25.8)	31(100)		
		Govt/Private Jobs							
	Female	Unemployed	06(10.9)	06(10.9)	14(25.5)	29(52.7)	55(100)	28.933	.001***
		Daily wager	07(43.8)	03(18.8)	00(00.0)	06(37.5)	16(100)		
		Farmer & self	09(60.0)	02(13.3)	01(06.7)	03(20.0)	15(100)		
		Employed	05(50.0)	03(30.6)	01(10.0)	01(10.0)	10(100)		
		Govt/Private Jobs							
Annual Income	Male	<25000	08(47.1)	03(17.6)	02(11.8)	04(23.5)	17(100)	8.334	.215
		25001-100000	29(47.5)	08(13.1)	10(16.4)	14(23.0)	61(100)		
		>100001	11(42.3)	10(38.5)	02(07.7)	03(11.5)	26(100)		
	Female	<25000	06(10.3)	08(13.8)	15(25.9)	29(50.0)	58(100)	27.599	.000***
		25001-100000	15(53.6)	04(14.3)	01(03.6)	08(28.6)	28(100)		
		>100001	06(60.0)	02(20.0)	00(00.0)	02(20.0)	10(100)		

the areas of intervention which could lift the socioeconomic condition of female caregiver of mentally ill patient.

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*Understanding Psychological Distress Among Female Caregivers***REFERENCES**

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Understanding Psychological Distress Among Female Caregivers

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