

Need for care to caregivers: Psychological distress and its socio-demographic correlates among the relatives of persons with mental illness

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Abstract

Background: The present study aims to compare the presence of psychological distress and its socio-demographic correlates among relatives of patients with mental illness and general public in Jharkhand.

Methods: 240 relatives of persons with mental illness and 240 general public were assessed for psychological distress using Kessler Psychological Distress Scale version 10 (K10).

Results: Psychological distress found among half of the total respondents at various levels. Relatives group reported higher levels of psychological distress than general public. The Spearman rank correlation shows significant positive correlation between psychological distress and gender, age, marital status and significant negative correlation between education, occupation and annual income.

Conclusion: The study reveals psychological distress is significantly higher among the relatives group. It indicates the need for support and guidance to the caregivers of persons with mental illness. More comprehensive strategies are necessary to sensitize individuals about broad aspects of mental health and motivating them for approaching treatment. At the same time there is also need for strategies to provide affordable and accessible care to the needy.

Key words: Psychological distress, care givers, relatives of person with mental illness, family, untreated mental illness.

Introduction:

Psychological distress is an outcome of various factors associated with an individuals' social, psychological and biological make up and environment. It is found to be associated with both physical and mental illness. The associations of psychological distress with mental illnesses are found to be bidirectional. That means the psychological distress can cause a mental disorder and at the same time mental illness itself may be the reason for psychological distress. The psychological distress may be the overt manifestation of an ongoing mental illness. Previous studies had found that socio economic conditions, social support, occupational and academic pressure and work conditions, aging, violence, addictive behaviors, migration, etc., may cause for psychological distress. Physical abuse, domestic violence, separation, isolation caused by widowhood, infected by deadly illness etc, may make women more vulnerable to psychological distress than men(Lindhorst, Oxford, & Gillmore, 2007; Torres & Wallace, 2013; Ferro, 2014; Liebana- Pressa et al, 2014; Shivkumar et al,2015; Cascardi 2016; Duchaine et al, 2017; Kachi, Abe, Ando & Kawada, 2017). High level of psychological distress can be an indicator for underlying mental illness. Remain unaddressed it may cause for worsening in terms of severity and dysfunction. The identification and appropriate management is important (Kessler et al, 2003).

The relatives of individuals with any kind of illness, whether it mental illness or physical illness are more vulnerable to have psychological distress. The distress associated with life threatening illness of the dear ones and the complications associated with care giving and financial burden often complicate the picture. By sharing a same genetic and psychosocial environment, the relatives of the individuals with mental illness are prone to have more psychological distress and mental health issues (Al-Gamal & Yorke, 2014; Ae-Ngibise, Doku, Asante & Owusu-Agyei, 2015; Sintayehu, Mulat, Yohannis, Adera & Fekade, 2015; Sanuade & Boatemaa, 2015).

Methodology

The present study was conducted in the Hazaribagh district of Jharkhand and it was a community based cross sectional study. The study carried out between the time period of July 2014 to February 2016. Total number of participants in the present study was 480 individuals consisted of 240 individuals living with a mentally ill person (Group 1) and 240 individuals from general population (Group 2). The sample size calculated on the basis of an approximate adult population of 12 lacks in Hazaribagh district with an expected 20% prevalence of mental illness as reported by the previous studies with a 95% confidence level and 0.05 confidence interval (Math & Srinivasaraju, 2010; Census Organization of India, 2011; Election Commission of India, 2014). Individuals living with a mentally ill person at least for last two years and who are either related with blood relations or marriage included in the group 1. The individuals with no family history of mental illness, not living with a mentally ill spouse, or a mentally ill child or any other person with mental illness were included in the group 2. Individuals with any kind of known mental illness, mental retardation, epilepsy, physical disability, chronic physical illnesses, unable to give a valid response due to any kind of physical limitation and age below 18 years and above 60 years were excluded from both groups.

The study is carried out with the support of Nav Bharat Jagriti Kendra (NBJK), a non-profit organization engaged in community psychiatry programmes in Hazaribagh district. They also work for the development of underprivileged and individuals with various disabilities in different part of Jharkhand. The organization shared a data base of more than 1400 individuals with mental illnesses in Hazaribagh district, which helped the research team to identify the relatives of mentally ill. To ensure the specific inclusion and exclusion criteria the present study used purposive sampling method. The respondents for general public group (group 2) were recruited from the same locality of the relative group by request to participate in the study. The data collected at the door step of the individual respondent. Informed written consent obtained from all participants.

A semi structured profile used for recording the socio-economic details of the respondents. Kessler Psychological Distress Scale version 10 used for recording the psychological distress (Kessler et al, 2003). Kessler Psychological Distress Scale is a simple scale consisted of ten questions with five levels responses to each question about the emotional status of the respondent from 'none of the time' to 'all of the time'. A

higher score in the measurement indicates higher levels of psychological distress ranging from 10 to 50. The measurement can be given to the respondent to complete or can be read to them by the practitioners (Kessler, 2003). As per cut offs adopted by the 2001 Victorian Population Health Survey, a score between 10 to 19 indicates likely to be well, a score between 20 to 24 indicates likely to have a mild disorder, a score between 25 to 29 indicates likely to have a moderate disorder and a score between 30 to 50 indicates likely to have a severe disorder (Victorian Population Health Survey, 2001). The questionnaire used in its original form in English language and the individuals who are unable to read and comprehend the questionnaire were helped by the trained volunteers of post graduate students. Frequency and percentiles used for comparing the socio-demographic variables, Mann-Whitney-u test used for comparing the level of psychological distress between groups and spearman's correlation coefficient used for assessing correlations.

Results

Table: 1 Socio- Demographic Profile of Relatives & General Public N=480

Variable		Group 1 Relatives of mentally ill people (n=240)	Group 2 General Public (n=240)
Age in years (between 18 to 60 years)	Less than 30 years	79 (32.9)	122 (50.8)
	31 -40 years	61 (25.4)	55 (22.9)
	41- 50 years	56 (23.3)	44 (18.3)
	51 and above	44 (18.3)	19 (7.9)
Gender	Male	106 (44.2)	163 (67.9)
	Female	134 (55.8)	77 (32.1)
Religion	Hindu	202 (84.2)	207 (86.2)
	Others	38 (15.8)	33 (13.8)
Family type	Nuclear	127 (52.9)	141 (58.8)
	Joint / extended	113 (47.1)	99 (41.2)
Marital status	Unmarried	40 (16.7)	78 (32.5)
	Married	191 (79.6)	157 (65.4)
	Widow/widower/ Separated/divorced	9 (3.8)	5 (2.1)
Educational status	Illiterate	65 (27.1)	25 (10.4)
	Below 10 th	90 (37.5)	71 (29.6)
	10 th pass	37 (15.4)	48 (20)
	Intermediate	22 (9.2)	55 (22.9)
	Graduate and above	26 (10.8)	41 (17.1)
Occupational status	Unemployed	97 (40.4)	16 (6.7)
	Daily wagers	48 (20)	72 (30)
	Farmers/ self-employed	53 (22.1)	53 (22.1)
	Professionals/ regular jobs	42 (17.5)	99 (41.2)
Family income in Indian rupees	Less than 25000	105 (43.8)	29 (12.1)
	25000 to 1 lack	96 (40.0)	127 (52.9)
	1 lack and above	39 (16.2)	84 (35.0)

As shown in table 1, large number of respondents of both groups was from the age category of less than 30

years (33 % and 51 % respectively). Females (56%) were majority in group 1 and males (68%) were in group 2 and most of them were from Hindu religion (84% and 86% respectively). Majority of the respondents belonged to nuclear families (53 % and 59 %) and married (65 % and 80%). In group 1 majority were low educated or illiterate (38 % and 27 %) whereas largest (40 %) number of respondents had an education of matriculation or intermediate in group 2. In group 1 large number (40) of respondents were unemployed and were earning income less than 25000 Indian rupees annually (44%). In group 2 largest (41%) number of people engaged in business or professional works and were reported annual earning income between 25000 to 1 lack Indian rupees (53%).

Table No2. Showing the presence and comparison of psychological distress among the relatives and general public (N=480)

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	Mean rank	Mann Whitney U	P
Relatives (n=240)	83(34.6)	39(16.2)	33 (13.8)	85(35.4)	25.37 ± 9.93	309.62	12211.5	.000***
General public (n=240)	180(75)	24(10)	18(7.5)	18(7.5)	15.84 ± 6.97	171.38		
Total	263 (54.8)	63(13.1)	51(10.6)	103(21.5)				

*** Significant at less than 0.001 levels

As table 2 shows nearly half of the total respondents reported to have psychological distress at various levels and among them 21 % of the total respondents reported likelihood for having severe disorder. As per the scores shown in table No.2, 16% of the relatives are likely to have mild disorders, almost 14% likely to have moderate disorders and 35% likely to have severe disorders. Among general public it was 10% for mild disorders, 7.5% each for moderate and severe disorders. The differences between groups found to be statistically significant at p-value less than 0.001 levels in Mann Whitney – U test.

Table No3. Showing Spearman’s correlation between psychological distress and socio-demographic variables

socio-demographic variables	Correlation coefficient
Gender	.247**
Age	.239**
Marital status	.166**
Educational status	-.348**
Occupational status	-.286**
Annual income	-.298**

** . Correlation is significant at the 0.01 level (2-tailed).

Table No.3 shows the details of spearman’s correlation analysis between psychological distress and various socio-demographic variables. The psychological distress positively correlated with gender, age and marital status. That means in comparison to male, female gender is more vulnerable to have psychological distress. Regarding marital status the psychological distress may increase from unmarried to married to widow/widower/separated/divorced. Educational status, occupational status and annual income found to be negatively correlated with psychological distress score. It means when a person has better educational, occupational and income status the psychological distress may be low and vice versa.

Discussion

The present study reveals that the presence of psychological distress at various severities among both study groups. The scores found to be higher among relative group compared to general public. Considering from mild level, almost 65% the relative group reported to have presence of psychological distress against 25 % in the general public group. It is also important to notice that almost half of the respondents in relative group scored for moderate or severe levels of psychological distress. The present study used Kessler Psychological Distress Scale for measuring psychological distress. The measurement has used widely to identify common mental disorders and found have very high reliability and validity and very least in various possible biases. A high score in the measurement indicate the possibility of an identifiable mental disorder. Higher the score higher the possibility of common mental disorders and the illness severity. In that way almost half of the total respondents are vulnerable to have some kind of mental disorders. In terms of severity almost half of the respondents in relative group and 15 % of the respondents' in general public group may have a common mental disorder with a severity of moderate or severe levels (Kessler et al, 2003; Baillie, 2005). Previous studies reported that the individuals are found to be reluctant to approach mental health facilities because of various reasons including stigma. And at the same time lack of knowledge and an inability to identify certain symptoms as mental illness or mental health problem are also reasons.

People usually understand severe symptoms like violence, self-harm and grossly disoriented behaviors as the symptoms of mental illness. The symptoms if not presented with such abnormalities, people may not pay attention. In that way many times the family and relatives might have brought individuals with psychotic disorders to any mental health facility, but the illnesses with less severity such as anxiety and somatoform disorders might have gotten ignored. The treatment gap in India estimated between ranges of 60-90%. That means a vast majority of individuals with mental health needs are not approaching any mental health facility and not receiving any support (Demyttenaere et al, 2004; Abbo, Ekblad, Waako, Okello & Mussi, 2009; Ham, Wright, Van, Doan & Broerse, 2011; Mwayo, Ndeti, Mutiso & Khasakhale, 2013; Sorsdahi, Flisher, Wilson & Stein, 2010). The untreated mental illness and mental health problems even in terms of stress will cost to the individual and society in multiple way. Firstly, it will cause for decreasing the functional ability of the sufferer at various levels. Secondly, it will cause for impairment in social and personal relationships. It is very important that when parents of younger children have any trouble, the care for them will be affected and it may hamper their present life and future development. Thirdly, the decreased ability in functioning may affect the individual's occupational performance and they may get trouble at work place. Indirectly any impairment in the occupational functioning may lead to a negative impact in nation's total production also (Patel & Knapp, 1988; Kingston, Tough & Whitefield, 2012; Kingston, McDonald, Austin & Tough, 2015). Mental disorder at level will lead to dysfunction in psychosocial functioning of the individual. The presence of psychological distress in almost half of the individuals in the present study indicates the likelihood of common mental disorders at various levels. The untreated illness will be causing for huge loss for the country and hence the identification and management is important. There is a huge difference between general public and relatives who are living with mentally ill people which indicates the need of strategies to identify the problems of the care givers and interventions to support them.

The correlates of the psychological distress indicate some of the remedial steps in a broad psycho-social frame work. It indicates the various domains in which they need help and support. As per the findings, the female gender is more vulnerable to psychological distress. Here it becomes a very complicated issue to discuss as there may be various mechanisms. The earning member of the family itself creates lot of disparity. In many families male may be an earning member and when a male member develop mental illness the family may lose their source of income. To compensate the needs many time the female members may go for various kinds of jobs, for which they may not be prepared. In another situation, the male members may be irresponsible to the family responsibilities and by force or for no other chance the female members may go for jobs. A third condition maybe the woman going for job as per her own will. In most of the cases the females will be key care taker for the patient and they will be overburdened with the care taking and duties. Other specific vulnerabilities for a woman to have more psychological distress are all kind of abuses, societal attitudes, socio-

cultural, religious and political biases, sex related health issues etc. Strategies to reduce gender differences, gender related violence, healthier attitude and favorable support from society may help to bring down the severity psychological distress among female population (WHO, 2000; Ramiro, Hassan & Peedicayil, 2004; Vizcarra et al., 2004; Kingston et al., 2015).

Present study also found that the psychological distress increases with age among the referred population. The reasons can be many such as more responsibilities associated with family and work, poverty and unemployment or uncertainty about job (Fukuda & Hiyoshi, 2012; Wang & Wang, 2013). Being unmarried is associated with lower psychological distress and being a widow/widower or separated or divorced is associated with higher psychological distress. Various studies investigated the association between marriage and psychological distress and the results are contradicting. In most of the studies it was found that loss of partner, being separated/ divorced is associated with highest level of psychological distress as like in the present study. Being single or married and its relationship with psychological distress found to be non-conclusive and different studies gave different opinions. The specific features of the sample such as age, socio-cultural background, social support etc., may have significant role in this. The increased responsibility such as job, care taking of the ill members, taking care of the children and stigma may also play important role (Hope, Rodgers & Power, 1999; Darghouth, Brody & Alegría, 2015).

Educational status also found to be correlated with psychological distress in the present study. Education plays the role of brushing out unawareness, increases the possibility of better life by helping a person to get high salary jobs. It help the individual to develop a set of skills and abilities to live better in the society (Araya, Lewis, Rojas & Fritsch, 2003; Zhang, Chen, McCubbin, McCubbin & Foley, 2010; Vijaylakshmi, Reddy, Math & Thimmaiah, 2013). The unemployment creates helplessness in supporting the family, their fooding and lodging, education, medicines etc., which compels the person to take risky, uncertain jobs and creates distress (Hoeing & Hamilton, 1966, Araya et al, 2003; Zhang et al, 2010; Cadieux & Marchand, 2014; Boschman, VanderMolen, Sluitor & Fringe- Dressen, 2013; Natalie, Ian, Steve & Paul, 2003). Income obtain from occupation also determines level of distress. In the present study the low income found to be correlated with psychological distress. Low income causes inability to perform the function as normal member of the society which includes the maintaining the day today needs of the family, education of children, health care needs, lifestyle and other comfort needs (Araya et al, 2003; Zhang et al, 2010; Lazzarino, Yiengprugsawan, Seubsman, Steptoe & Sleight, 2014; Caron & Liu, 2011; Pongsavan, Chey, Bauman, Brooks & Silave, 2006).

The subjects of the present study are not recognizing that they have any mental illness or problem and hence not approach for help. In this context a strategic intervention to spread awareness among the population about mental illnesses and mental health problems and motivate them for consultation is important. The knowledge should be broadened and the barriers in approaching treatment facilities should be addressed. Ongoing illness and problems associated with psychopathology, burden in different domains, poor coping, lack of social support and the shared genetic vulnerability may be causing for increased level of psychological distress among relatives (Engel, 1977; 1978; Scottish Schizophrenia Research Group, 1987;1988; Ostman & Kjellin, 2002; Kohn, Saxena, Levav, Saracen, 2004; Schulze & Rossler, 2005; Sanuade & Boatemaa, 2015; Sintayehu, Mulat, Yohannis, Adera & Fekade, 2015). The socio-demographic correlates found in the present study may have implications on developing helping strategies for the relatives and general public in different ways. Strategies for lowering gender inequalities and gender related violence and support to woman is very important. There should be strategies to promote better education and job opportunities to woman. Men's participation in house hold activities should be increased. The mental health facilities should be available locally as part of primary health care and there should be strategies to make individuals generalize it as like any other physical illness. The individuals should be motivated to speak about their mental health related difficulties and benefits from the treatment. Affordable and accessible care, promising results from treatment strategies, proper education about all aspects of the illness, specific training in illness management skills etc., may help the individuals and relatives to cope better with the illness and situations. Support should be provided for restoring wellbeing through various skills training programmes especially occupational skill training, job search and other income generation activities. The burden to the caregivers and distress associated with can be reduced

effectively by providing facilities for day care, half way homes and self-help groups.

The limitations of the study which have been observed are the data of the study was unmatched for all variables such as gender, caste, age, occupation, education etc. The generalization becomes difficult as researcher used purposive sampling. There may be separate specific vulnerabilities for relatives and general public to have psychological distress, which is not addressed in the present study adequately. Also even with severe level of distress, why people especially the relatives are not approaching for treatment as it is available at their reach is also not answered. There is need for more studies using better sampling strategies to address such issues which will bring more clarity to the policy makers and professionals to address these issues more appropriately.

In conclusion, present study brought many significant findings despite having limitations discussed above. The study reveals the possibility of presence of unidentified psychiatric morbidity among the study population. All the participants in the present study never approached any mental health facility for help and may remain with their problems if no interventions initiated. A systematic and comprehensive strategy needed for sensitizing the community against their needs. There is need for more attention to provide proper, affordable and accessible care to the community.

Conflict of interests: On behalf of all authors the corresponding author states that there is no conflict of interest

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