

ORIGINAL ARTICLE

Psychological Distress, Subjective Burden and Stigma among Caregivers of People with Mental Illness in Gondar University Hospital, Ethiopia

Lelsie Bekuma¹, Mastewal Ababaw² and Steve Melliush³

Abstract

Care givers play a vital role in supporting their own relatives who are mentally ill, infirm who have disabilities. There is concern that the families of those with mental disorders are affected by the condition of their loved ones. The main purpose of this study was to assess the psychological distress, subjective burden and stigma among caregivers of people with mental illness in University of Gondar Hospital. Three hundred and eighty-five caregivers (M=134 and F=251) were selected using simple random sampling technique. Data were collected through Self-Report Questionnaire (SRQ-20), Experienced Stigma Scale (the Family Version) and Caregivers' Burden Inventory (CBI). Data was checked, coded, entered and analyzed using SPSS version 20. Descriptive and inferential data analysis techniques like percentage, independent sample t-test, one-way ANOVA, Linear and multiple regression were employed. Data analyses showed that a bit higher 203 (52.7%) of primary care givers of mentally ill patients were psychologically distressed. Besides, 247(64.2%) caregivers of mentally ill patients experienced high subjective burden. The majority of them also faced stigma as a result of being caregiver of mentally ill patients. Stigma and subjective burden significantly predict psychological distress, indicating that as stigma and subjective burden increase, psychological distress also increases. Male and female caregivers significantly differ in psychological distress. Most importantly, caregivers of mentally ill patients manifested symptoms of psychological distress, subjective burden and stigma. Therefore, due attention should be given for caregivers of people with mental illness.

Keywords: Psychological distress, Subjective burden, Stigma, and Caregivers

Introduction

Caregivers play a vital role in supporting close relatives who are mentally ill, infirm and who have disabilities. There is concern that the families of those with mental disorders are affected by the condition of their near ones (Shan, et al., 2010). Effective family functioning and psychological wellbeing in families with mental illness (which are considered to be primary caregivers) are influenced by a variety of psychosocial factors (Sanders, 2003).

The substantial and growing public health burden arising from mental disorders (MDs) across the world has been well documented (Ostman & Kjellin, 2002). The burden of MDs is estimated as 14% globally (Shu & Lung, 2005), with the highest burden in developing countries (Rush, 2010). Study conducted by Green (2007) found out that MDs have considerable negative consequences on the quality of life of patients and their caregivers or friends, particularly in low- and middle-income countries.

1 University of Gondar Hospital, Clinical Psychology and Counseling Unit, Gondar, Ethiopia

2 Lecturer at Department of Psychology, College of Social Sciences and the Humanities, University of Gondar, Ethiopia. E- mail; mastiman1@yahoo.com

3 Doctorate in Clinical Psychology and Director of Clinical Practice at Department of Neuroscience, Psychology and Behaviour, University of Leicester, Centre for Medicine.

World Health Organization (2006) reported that in sub Saharan countries including Ethiopia, mental illness is not well addressed in services and there are limited trained professionals in comparison with the number of populations. Thus, relatives are forced to be the sole caregivers to their mentally ill relatives. This may result in an increase in the families' daily responsibilities and sources of stress at a time when they are also dealing with the uncertainty and stigma of chronic psychiatric illness. Besides, this causes psychological disorder of mental ill caregivers (Cook, et al., 1994).

Research on the impact of care giving shows that one third to one half of caregivers suffer from psychological distress and experience higher rates of mental health problems than the general population (Shan, et al., 2010). In Ethiopia, assessing the mental health of primary care- givers has got lesser attention. Thus, the main objective of this study was to assess the psychological distress, subjective burden and stigma among caregivers of mental ill patients.

Methods

Research Design

A quantitative research with cross-sectional survey design was employed to assess the psychological distress, subjective burden and stigma among caregivers of people with mental illness.

Participants and Sampling

The University of Gondar hospital psychiatry wards have 21 beds including two emergency beds with two outpatient departments (OPDs). On average, 40 people with mental illness thought to have visited the University Psychiatry ward with their family members both in inpatient and outpatient units. At the time of data collection, the estimated number of caregivers who visited the hospital were 1200. Considering the total number of the population, 385 caregivers were selected using simple random sampling technique with margin error of 5 % and 95 % confidence interval.

Table 1: Demographic profile of the participants

Variables	Categories	Frequency	Percent
Sex	Male	134	34.8
	Female	251	65.2
	Total	385	100
Religion	Orthodox	322	83.6
	Muslim	63	16.4
	Total	385	100
Marital status	Married	198	51.4
	Single	160	41.6
	Divorced	12	3.1
	Widowed	15	3.9
	Total	385	100
Educational level	Illiterate	85	22.1
	1 – 8 grade	87	22.6

Variables	Categories	Frequency	Percent
	9 – 12 grade	95	24.7
	Above 12 grade	118	30.6
	Total	385	100
Relationship with the patient	Father	52	13.5
	Mother	37	9.6
	Sibling	154	40.0
	Other Relationship	142	36.9
	Total	385	100

Data collection tools and procedures

Researchers developed questionnaire is used to collect socio-demographic characteristics of the caregivers. The second part of the questionnaire is self-report questionnaire (SRQ-20) developed by WHO in order to screen psychiatric disturbances and levels of distress in developing countries. SRQ-20 has been adopted, validated and translated into the Ethiopian language (Amharic). These instruments were used in previous studies (Tafari, et al., 1991, Abateneh, et al., 2013).

The questionnaire consists of 20 items which include the symptoms of depression, anxiety, cognitive disturbance, somatic symptoms, and behavioral disturbances like decreased energy. Each of the 20 items of SRQ is scored as 0 or 1. A score of 1 indicates that the symptom was present during the past 30 days. A score of 0 indicates that the symptom is absent. The maximum score is therefore 20. Respondents who score 7 and above were considered as having psychological distress, and respondents who report 6 or less symptoms were considered as not having psychological distress.

The third part of the questionnaire assesses Stigma Experience Scale of the Family Version. From the total seven items of stigma experience scale of the family version, the first four items are scored on a 5-point Likert-type scale. That is 'never', 'rarely', 'sometimes', 'often', and 'always'. Items are then recoded into binary variables to reflect the presence or absence of each specific stigma experiences. So, 'never', 'rarely' and 'sometimes' are recoded as zero to reflect the absence of stigma and 'often' and 'always' are recoded to reflect the presence of stigma. The rest three items are scored using the response categories (yes, no, unsure) and recoded by 0 and 1 to reflect the presence (yes) is coded as 1 or absence (no and unsure) is coded as 0. Values are then summed across the seven items for a scale and the score is ranging from 0 to 7. So, the increase in the score of scale shows that respondents are experiencing more stigma and low scores show that respondents are experiencing lower levels of stigma. The coefficient of reliability for this scale is (KR-20=0.76). This proves that the scale achieved an acceptable level of internal consistency.

This research also employed 21 items Caregivers' Burden Inventory (CBI) that showed to have excellent psychometric properties (Chou et al. 2002). Subjective burden was assessed in five areas; emotional burden, social burden, time-dependent burden, developmental burden and physical burden. This scale has 63 total score and its cutoff point is; 0 = families have no burden, 1-21 = families have minimum burden, 22-42 = families have moderate burden and 43-63 = families have high burden.

Pilot Testing

The researchers of this study conducted pilot study that assessed reliability of the measures. For this purpose, 30 caregivers of people with mental illness were randomly taken from Felege Hiwot Hospital psychiatry wards. This site was chosen due to the fact that the inhabitants have common language and relatively same cultural background with the participants of the current study. The internal consistency of psychological distress was $\alpha = 0.667$, stigma experience was $\alpha = 0.872$ and subjective burden scale was $\alpha = 0.81$. Data processing and analysis

Data clean up and cross-checking were done before analysis. Next, data were checked, coded, entered and analyzed using SPSS version 20. Descriptive statistics like the mean, percentage, and standard deviations were used for data summarization and description. Inferential statistics like correlation, multiple linear regression and independent samples t-test were used in order to see whether mean difference exists across sex.

Ethical considerations

Ethical clearance was obtained from Ethical review board of University of Gondar. The board approved that the study was in line with research ethics and it has no harm on the respondents. Besides, permission to conduct the research was obtained from Hospital administration. After explaining the purpose of the study, written consent was obtained from caregivers. Anonymity was employed and thus the participants' identifications were not registered in the format to ensure confidentiality. It was explained to the participants that they have the right not to respond for questions that are not comfortable for them. Finally, the questionnaires were kept locked after data entry was completed.

Results and Discussion

Prevalence of psychological distress, stigma and subjective burden

The prevalence of psychological distress, stigma and subjective burden among caregivers was calculated and presented in the following table.

Table 2: Prevalence of Psychological Distress, stigma and subjective burden among Caregivers (n=385)

Variables	Categories	Frequency	Percent
Psychological distress	Non-distressed	182	47.3
	Distressed	203	52.7
	Total	385	100
Stigma	Stigmatized	307	79.74
	Non-stigmatized	78	20.26
	Total	385	100
Subjective burden	Minimum Burden	16	4.2
	Moderate Burden	122	31.6
	High Burden	247	64.2
	Total	385	100

As displayed in Table 2, a little above half (52.7%) of the caregivers were distressed whereas the remaining 47.3% did not experience psychological distress. To the worst, the majority of caregivers (79.74%) reported that they were being stigmatized. Besides, the results indicated that more than half (64.2%) of caregivers experienced high level subjective burden. The remaining 31.6% and 4.2 % of the caregivers reported moderate and minimum level of subjective burden, respectively.

Relationship between stigma and psychological distress

The relationship between stigma and psychological distress among mentally ill caregivers is presented in the following table:

Table 3: Correlation among variables

Variables	1	2	3	4	5	6	7
1.Sex	-						
2. Age	-.142**						
3.Religion	.133**	-.056					
4.Marital status	.129*	-.178**	.091				
5.Educational status	.254**	-.438**	-.014	-.119			
6.Stigma	.101*	.004	.024	-.026	-.088		
7.Subjective burden	.069	.019	.075	-.009	.028	.217**	
8.Psychological Distress	-.029	.034	-.114	.190**	.049	.299**	.173**

** . Correlation is significant at the 0.01 level and * . Correlation is significant at the 0.05 level

Table 3 indicates positive relationship between stigma and psychological distress (r=0.299 n=385, p<0.05). This indicates that a high level of stigma is associated with to high level of psychological distress. Similarly, stigma and psychological burden were positively correlated (r=0.299 n=385, p<0.05). And, there is a weak positive relationship between stigma and subjective burden (r=0.217, n=385 p<0.05), indicating that as stigma levels increase levels of subjective burden also increase Besides, psychological burden was significantly and positively correlated with psychological distress (r=0.173, n=385 p<0.05).

Table 4: Caregivers Stigma, Subjective Burden and Psychological Distress across Sex

		N	Mean	SD	df	t	Sig.	95%CI
								Lower Upper
Distress	Male	222	10.18	3.948	183	1.99	.047*	-1.59 .01
	Female	163	10.98	3.820				
Stigma	Male	222	5.28	2.472	183	1.36	.175	-.818 .150
	Female	163	5.61	2.262				
Burden	Male	222	43.58	9.686	183	.56	.571	-1.406 2.547
	Female	163	43.01	9.832				

* Significant at the 0.05 level (2-tailed).

An independent samples t-test was conducted to compare the psychological distress, stigma and subjective burdens between male and female participants. There was significant difference in psychological distress burden between male and female caregivers (t ($df=183$), $t=1.99$, $p<.05$). Female caregivers scored higher in psychological distress (mean =10.98) than male caregivers (mean = 10.18). However, male and female caregivers did not significantly differ in stigma (t ($df=183$), $t=1.36$, $p>.05$) and subjective burden ($df=183$), $t =.56$, $p>.05$).

Table5: Multiple regression predicting psychological distress

Variables	Model 1(β)	Model 2(β)
Sex	.097	.080
Age	.029	.043
Religion	.015	.016
Marital status	-.044	-.017
Educational status	.046	.060
Stigma		.258**
Subjective burden		.182**
R ²	.014	.129**
Δ R ²		.115**

** . Correlation is significant at the 0.01 level

Multiple linear regression was conducted to see the predicting role of demographic variables, stigma and subjective burden on psychological distress. Model 1 above shows that demographic variables did not significantly explain psychological distress ($= .014$, $p >.05$). Taken together in Model 2, demographic variables, stigma and subjective burden significantly explained 12.9 % of psychological distress ($= 12.9$, $p<.05$).

After controlling the possible effects of demographic variables, stigma and psychological burden explained additional 11.5 % variance in psychological distress ($\Delta = .115$, $p<.05$). Stigma ($\beta =.258$) was found to be the stronger predictor of psychological distress than subjective burden ($\beta =.182$).

Prevalence of Psychological distress among caregivers of mental illness

The finding of the current study revealed that out of the total samples, about 52.7% of them were psychologically distressed, scoring 7 and above in the SRQ 20. Similarly, Witmund, Wilms, Mory & Anger Meyer (2002) suggested that being a caregiver for mentally ill patients is connected with poor psychological wellbeing which leads to a higher risk of developing psychological distress. Likewise, a study conducted in Nigeria demonstrated that 79.84% of caregivers of people with mental illness were emotionally distressed (Yesuf and Nuhu, 2011).

Consistent with present study, a hospital-based study by a group of researchers (Shah, Sultan, Faisal & Irfan, 2013) found out psychological distress among caregivers of people with mental illness. Out of the total participants, majority of the caregivers (72%) were found to have a score of 9 or more on SRQ-20 and were found to be distressed, indicating higher level of psychological distress among the caregivers.

Relationship of Demographic characteristics with stigma, psychological distress and subjective burden

The findings of the current study show that demographic variables (sex, age, religion, marital status and educational level) did not have significant association with psychological distress, stigma, and psychological burden. This is inconsistent with some previous studies. For instance, caregivers who are in younger age were found to be at a higher risk of developing psychological distress (McDonnell et al., 2003; Gutierrez, et al., 2005; Stengard & Salokangas, 1997). One possible explanation for this can be the cultural difference. Unlike the current study, lower educational level was found to be more related to psychological distress. For example, Magna, et al (2007) found out those caregivers of mentally ill people with higher levels of education reported less burden and distress. The current study shows that the level of education did not significantly correlate with level of psychological distress, stigma and psychological burden among caregivers of people with mental illness. The disproportionate distribution of the participants across different literacy level might have caused insignificant relationship with psychological distress.

However, the finding of the current study shows a significant difference in psychological distress between male and female caregivers. That is, female caregivers experienced more psychological distress than male caregivers. This is consistent with previous studies which explain that females are more vulnerable to psychological distress in the care giving role than do males (McDonnell, et al, 2003; Gutierrez, et al., 2005; Baronet, 1999; Stengard & Salokangas, 1997). It is also well documented that women tend to be vulnerable to depression than men (Idstad et al., 2010).

Predicting psychological distress

Demographic variables, stigma and subjective burden significantly explained 12.9 % of psychological distress. After controlling the possible effects of demographic variables, stigma and psychological burden explained additional 11.5 % variance in psychological distress. Stigma found to be stronger predictor of psychological distress. This indicates that, with high levels of stigma there is high levels of psychological distress. Similarly, a study by Magna et al (2007) and (Tantawe, et al, 2010) revealed that stigma increased caregivers' depressive symptoms.

Conclusion

Most caregivers of mentally ill patients in Gondar University Hospital experienced high subjective burden and were psychologically stressed. This indicates high prevalence of psychological distress and psychological burden among caregivers of mentally ill patients. The majority of caregivers experienced stigma for being caregiver of mentally ill patients. Under these conditions, as compared to male caregivers, female caregivers encountered higher degree of psychological distress. Stigma and subjective burden were significantly correlated with psychological distress. The prevalence of psychological distress found high among caregivers in this study. Thus, mental health professionals (clinical psychologists, psychiatrists, nurses, and social workers) are recommended to support not only mentally ill patient but also their caregivers.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the authorship and/or publication of this article.

Author's Contribution

Lelesie contributed in problem identification, first proposal preparation and presentation, data collection, preformed statistical analysis and final report writing and presentation. Mastewal advised method section and analysis part, and drafted and edited the manuscript. Steve worked on the manuscript

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