Abebaw Fekadu. *Ethiop Med J, 2020, Vol. 58, No. 2*

## ORIGINAL ARTICLE

# LIVING WITH HIGH BURDEN OF CARE: EXPERIENCE OF CAREGIVERS OF PEOPLE WITH SEVERE MENTAL ILLNESS IN RURAL ETHIOPIA

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## ABSTRACT

***Introduction****: Caregivers of people with severe mental illness experience substantial burden from providing care. This burden is likely to be higher in low- and middle-income countries where statutory medical and social services are in low supply.*

***Objective:*** *We conducted a study aiming to evaluate the level of caregiver burden among caregivers of people with severe mental illness.*

***Methods****: The study was population-based cross-sectional evaluation carried out in the Sodo district of the Gurage zone in south Ethiopia. Three hundred people with severe mental illness and matched caregivers were included. The involvement evaluation questionnaire, a widely used tool for assessing caregiver burden, was administered. The involvement evaluation questionnaire has four domains (urging, worry, supervision and tension).*

***Results****: Caregivers were predominantly women (52.5%), married (67.6%), under 45 years of age (57.5%) and had little or no formal education (60.9%). The overall mean burden score (95% confidence interval (CI)) was 45.3 (43.2, 47.4); highest for "urging" (mean=15.5; 95% CI=14.6, 16.4) and "worrying" domains (mean=13.7; 95% CI=12.9, 14.4). Being female caregiver, first degree relative, experiencing distress and caring for patients with higher levels of symptomatology and disability were significantly associated with higher overall burden score.*

***Conclusions:*** *As anticipated, caregivers in this setting have higher levels of burden of caring compared with care givers in Europe and other settings. Interventions should aim not only at decreasing patient symptoms and improving functionality, but also at decreasing caregiver distress focused on women and first-degree relatives.*

*Key words: Burden of care, Caregivers, Mental Illness, Ethiopia*

## INTRODUCTION

Severe mental illnesses (SMI), such as schizophrenia and mood disorders with psychotic features, often result in substantial burden on patients and those providing care for them (1). For those providing care, the experience may be both positive and negative. The positive experience relates to the satisfaction and self-esteem caregivers may feel due to providing care, whereas the negative impact may result from the dissatisfaction and distresses that the caregiver may perceive related to caregiving (2).

These negative experiences are often referred to as burden (3), signifying the presence of problems, difficulties or adverse events affecting the lives of the members of patients' family (4).

Burden could also be understood as objective or subjective. Objective burden is related to the negative impact of caregiving on the caregiver's routine activities and subjective burden referring to the emotional impacts (5).

"Caregiver consequences" is a more neutral term that comprises both the negative and positive aspects of caregiving (1); however, the terms caregiver burden and consequences are often used interchangeably.

While the level of burden due to providing care is generally high (6,7), the level is relatively higher among caregivers of patients with SMI than that of caregiver's of patients with chronic medical conditions (8). Moreover, the burden is also likely to be higher in low and middle income countries (LMICs) like Ethiopia, where statutory medical and social services are unavailable or in short supply and people with SMI obtain most of the care they need from their families (6).

To our knowledge very few studies have been conducted in Ethiopia or other LMICs pertaining to caregiver burden. Those studies used Family Burden Interview (FBI), a measure of objective burden (6), and reported considerable level of burden, particularly related to finances,

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among caregivers of patients with SMI. A subsequent follow-up study (9) indicated that care giver burden does improve over time although this was more likely among in care providers of patients whose symptoms have improved or were experiencing sustained remission.

The aim of the present study was to evaluate the consequences of caregiving among caregivers of people with SMI using a tool that assesses both subjective and objective burden of caregiving. The study also aims to identify illness related and sociodemographic correlates of caregiver consequences. We hypothesized that caregivers of people with SMI experience higher levels of burden and that as disability and symptom severity increases caregiver burden increases.

## PATIENTS AND METHODS

***Study setting and design:*** The study was a population-based cross-sectional survey of patients with SMI and matched caregivers conducted in the Sodo district of the Gurage Zone in Ethiopia. The capital city of the district, Bui, is located about 100 km from Addis Ababa. At the time of the study, the district had 58 sub-districts, four urban and 54 rural, and the population of the district was about 170,000. Healthcare was provided by one primary hospital, eight primary health centers and 58 health posts.

***Participants*:** Participants were recruited from December 2014 to July 2015. Patients were first identified and then matched with a caregiver, who would have typically accompanied the patient. Caregivers were invited explicitly to accompany the patient during the day of assessment. This was possible because of the case identification and referral processes that were in place for the study. If the appropriate caregiver (inclusion criteria below) had not accompanied the patient, they were given another appointment to do so.

Patients with SMI were identified through a two-stage process. First, potential cases with psychosis were identified and referred by community key informants, consisting of health extension workers and community leaders trained for half a day by a psychiatrist with experience in training key informants. Second, these potential cases were referred to the health centres where trained psychiatric nurses conducted a semi-structured interview to confirm diagnosis and evaluate other clinical parameters, such as symptom severity. To be included in the study, participants had to be at least 18 years of age, fulfil diagnostic criteria of the International Classification of Diseases (ICD) for one of the major psychotic disorders (ICD-10 F20 and ICD-10 F30 [psychotic subsections]), be in need of mental health care at the time of detection, and were resident in the area for at least six months. The inclusion criteria for caregivers were; age 18 years and above, being a primary carer of a patient with SMI and that the carer is not being paid for providing the care, i.e., were informal caregivers.

***Sample size:*** Three hundred carers providing care for 300 patients who have received a diagnosis of SMI were recruited to take part. All consenting participants during the study period were included and no formal assessment of sample size was carried out. However, the sample size was adequate for the aims of describing the levels of carer burden and to assess key factors that may be associated with the burden.

***Measures:*** Socio-demographic information of the patients including their age, gender, ethnicity, marital status, religion, educational background, employment status, relative wealth and residence was collected. Moreover, other instruments that assesses the clinical, social, physical and psychological parameters were administered.

Trained psychiatric nurses administered the clinical assessment instruments whereas the other instruments were administered by trained and experienced lay data collectors. We used the Amharic version of the Involvement Evaluation Questionnaire (IEQ) to measure the burden of caregivers of people with psychotic disorder. Some of the instruments used are summarized below.

***OPCRIT (Operational Criteria for Research):*** is an operational criteria checklist for psychotic and affective illnesses. It was used in this study to confirm clinical diagnosis of SMI. OPCRIT has proven reliability to diagnose large number of mental disorders (10).

***Brief Psychiatric Rating Scale- Expanded version (BPRSE):*** is a 24-item instrument used to measure the overall clinical symptom severity. The items cover symptoms of psychosis, depression, mania, anxiety and somatic concern. The instrument has been used previously in Ethiopia and has shown high internal consistency and reliability (11).

***WHODAS (World Health Organization Disability Assessment Schedule), version 2.0***: measures the level of difficulties individuals have over the previous 30 days due to a health condition.

The instrument covers 6 domains: understanding and communication, getting around, self-care, getting along with people, life activities and participation in society (12). The WHODAS 2.0 has been adapted for use in Ethiopia (13).

***The Involvement Evaluation Questionnaire (IEQ):*** IEQ is a reliable and valid instrument, which assesses burden of caregiving on the basis of the perception of caregivers. It is an 81-item questionnaire to be completed by the caregivers of the patient. The Questionnaire has seven parts: a core section and six additional sections. The additional sections comprise questions about socio-demographics of the patient and the caregiver and contact variables; extra financial expenses; the General Health Questionnaire (GHQ-12), as measure of caregiver distress; professional help for the caregiver; consequences for patient's children; and one open question for additional remarks.

The core section of IEQ (27 items) assesses how often the caregiver experienced a burden in relation to caring during the previous 4 weeks. All items are scored on 5- point Likert scales (never, sometimes, regularly, often, and always). The items can be summarized as a total score or under the four domains: tension (9 items), supervision (6 items), worrying (6 items) and urging (8 items). Note that two items (items 29 and 43) are used in more than one domain. This means that the total score must be computed from the separate 27 items and not by just adding up the four subscales.

The domain "tension" refers to the interpersonal problem between patient and the caregiver; "urging" is the encouragement and motivation provided to the patient; "supervision" refers to the actual day to day care and guarding from danger; "worrying" refers to concerns related to patient's health and safety. Higher scores mean higher levels of caregiver burden. The instrument was translated and validated in several languages and used in different cultures such as in the EPSILON (European countries in European Psychiatric Services: Inputs Linked to Outcome domains and Needs) study involving five European countries (England, Netherlands, Spain, Italy and Denmark) (1,14) and several other countries (15-20).

The IEQ was translated into Amharic carefully through a consensus process by researchers with clinical and social science background and many years of experience in instrument translation and psychosocial research. The internal consistency and structure of the IEQ were also assessed. Although the IEQ is a self-administered questionnaire, in our case it was administered by trained and experienced lay data collectors. This was because most of the participants did not have adequate literacy to complete the IEQ.

***Ethical approval***

Ethical approval was obtained from the College of Health Sciences Institutional Review Board, Addis Ababa University (PSY/084/14). All families approached consented to participate.

***Statistical analysis***

The data were double entered using epidata version 3.1 and analyzed using the Statistical Package for Social Sciences (SPSS) version 12. We used a descriptive statistic for summarising the socio-demographics and the care profile of the study participants. We computed Cronbach's alpha values for internal consistency.

We run factor analysis and CFA in order to see the dimensions of the instrument. The 95% confidence intervals (CI) for the mean value were calculated whenever appropriate. We run bivariate and multivariate linear regression models to examine the association between IEQ total scores and patient and caregiver characteristics. We also used the mean scores of the total IEQ items and the domains for comparing the pattern of scores with some international data.

## RESULTS

***Participants and level of caregiver burden:*** Most caregivers were females (52.5%), married (67.6%), under 45 years of age (57.5%) and with little or no formal education (60.9%) (Table 1).

Caregivers were mainly first-degree relatives (84.7%)--children of the patients, spouses, siblings and parents--who lived in the same house with the patient (Table 2). Majority of cared for patients had schizophrenia spectrum disorder (85. 6%) with a small minority (14.7%) diagnosed with an affective psychosis.

***Reliability of IEQ***

The IEQ demonstrated relatively high internal consistency with Cronbach's alpha of 0.89 (for all the items). The four domains have also shown relatively high consistency (worrying=0.87, urging = 0.86, tension= 0.82 and supervision= 0.78). The factor analysis demonstrated that the 27 items load in to four factors, as in the original structure of the instrument and consistent with the above four domains (Worrying, urging, tension and supervision). Confirmatory factor analysis (CFA) showed that the total sum score of the IEQ can also be used on its own in addition to the four domains.

**Table 1:** Background characteristics of psychotic patients and their caregivers, Bui District, Ethiopia, December 2014 - July 2015.

| Background Characteristics | | Caregivers (n=299) | | Patients (n=300) | |
|---|---|---|---|---|---|
| | | Number | Percent | Number | Percent |
| Sex | Male | 142 | 47.5 | 172 | 57.3 |
| | Female | 157 | 52. 5 | 128 | 42.7 |
| | <25 | 46 | 15.4 | 65 | 21.7 |
| Age | 25-34 | 50 | 16.7 | 82 | 27.3 |
| | 35-44 | 76 | 25.4 | 79 | 26.3 |
| | 45-54 | 62 | 20.7 | 46 | 15.3 |
| | 55-64 | 46 | 15.4 | 15 | 5.0 |
| | ≥ 65 | 19 | 6.4 | 13 | 4.3 |
| Marital Status | Single | 50 | 16.7 | 136 | 45.3 |
| | Married | 202 | 67.6 | 111 | 37.0 |
| | Divorced/ widowed | 47 | 15.7 | 53 | 17.7 |
| Religion | Christian | 289 | 96.7 | 289 | 96.3 |
| | Other | 10 | 3.3 | 11 | 3.7 |
| Ethnicity | Gurage | 281 | 93.9 | 284 | 94.7 |
| | Other | 18 | 6.1 | 16 | 5.3 |
| Education* | Illiterate | 123 | 41.2 | 157 | 52.5 |
| | Can read and write | 59 | 19.7 | 53 | 17.7 |
| | Formal education | 117 | 39.1 | 89 | 29.8 |
| | Agricultural work | 108 | 36.24 | 76 | 25.5 |
| Employment** | Self employed | 41 | 13.76 | 16 | 5.37 |
| | Housewife | 93 | 31.21 | 58 | 19.5 |
| | other employments | 52 | 17.45 | 38 | 12.8 |
| | Unemployed | 4 | 1.34 | 110 | 36.9 |
| Residence* | Urban | 66 | 22.1 | 60 | 20.1 |
| | Rural | 233 | 77.9 | 239 | 79.9 |
| Relative wealth | Very low and low | 152 | 50.8 | 191 | 63.7 |
| | Medium and above | 147 | 49.2 | 109 | 36.3 |

**Table 2:** Profile of caregivers of patients with severe mental illness, Bui District, Ethiopia, December 2014 - July 2015

| Care characteristic | | Number | Percent |
|---|---|---|---|
| live in the same house with patient | No | 51 | 17.1 |
| | Yes | 247 | 82.9 |
| Relationship with patient | Parent | 23 | 7.7 |
| | Sibling | 60 | 20.1 |
| | Child | 105 | 35.1 |
| | Spouse | 64 | 21.4 |
| | Other family member | 47 | 15.7 |
| Lived together weeks | None | 3 | 1.03 |
| | Some days | 40 | 13.7 |
| | The full 4 weeks | 251 | 85.4 |
| Average time spent together | Less than 32 hours per week | 64 | 21.4 |
| | More than 32 hours per week | 235 | 78.6 |

***Caregiver burden and clinical and socio demographic correlates***

The overall mean scores (95% Confidence Interval (CI) was 45.3 (43.2, 47.4) with mean domain scores of 15.5 for urging, 13.7 for worrying, 10.0 for supervision, and 9.7 for tension domains (Table 3).

**Table 3:** Caregivers' burden and mean Involvement Evaluation Questionnaire score by domain, Bui District, Ethiopia, December 2014 - July 2015 (n=299)

| Burden domain | Mean | 95% Confidence Interval | Range Min, max |
|---|---|---|---|
| Urging* | 15.5 | 14.6, 16.4 | 0, 32 |
| Supervision* | 10.0 | 9.3, 10.7 | 0, 24 |
| Tension** | 9.7 | 8.9, 10.5 | 0, 36 |
| Worrying** | 13.7 | 12.9, 14.4 | 0, 24 |
| Total IEQ score | 45.3 | 43.2, 47.4 | 4, 107 |

Considering individual items of care involvement (Figure 1), encouraging patient to self-care (95%) and to eat (92%), and concern about the future of the patient (92%) were the most commonly endorsed burden items.

Concern about the general health of the patient, safety and managing finances without help from the care giver were endorsed by about four in five participants. Experience of burden of care was also endorsed by a similar proportion.

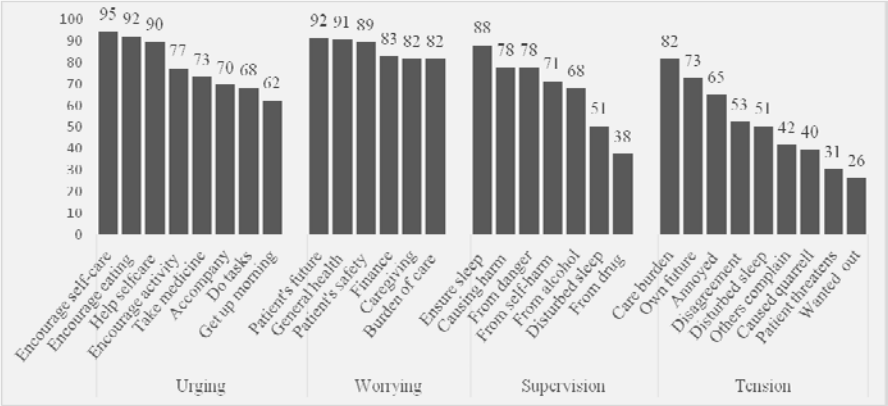


**Figure 1:** Percentage of caregivers endorsing individual items of the care sections of involvement, Bui District, Ethiopia, December 2014 - July 2015 (n=299)

In the unadjusted regression model (Table 4), sociodemographic characteristics of carers (female sex and being married), care characteristics (being first degree relative, living with patient and spending more than 32 hours per week with the patient), severity of illness in patient (high symptomatology and disability) as well as mental health of the carer (higher GHQ score) were associated with higher caregiver burden scores.

Formal education, employment status and higher relative wealth status were associated with lower caregiver burden scores. However, in the fully adjusted regression model (Table 4), only caregivers' sex (Adjusted mean difference=6.66; 95% CI=-0.01, 13.34; p=0.05), relationship with the patient across all first degree relatives compared with other relatives [Adjusted mean difference scores and p values for a parent caregiver 10.60, P< 0.01; child 8.82, P= 0.01; spouse 7.66, P< 0.02 and a sibling 8.53, P= 0.04)] were associated significantly with carer burden. High levels of symptomatology (Adjusted mean difference=0.16; 95% CI=0.03, 0.28; p=0.02) and disability (Adjusted mean difference=0.25; 95% CI=0.15, 0.34; p<0.01) in patient and high mental distress score in caregiver (Adjusted mean difference=0.45; 95% CI=0.13, 0.77; p=0.01) were also associated significantly with caregiver burden. The model explained 27.6% of the variance in caregivers' burden (Adj. $r^2$ = 27.64).

**Table 4:** Socio-demographic and clinical factors of caregivers associated with care burden, Bui District, Ethiopia, December 2014 - July 2015

| | Caregiver characteristics | Crude mean Difference | 95% Conf. Interval | | Adjusted mean Difference | 95% Conf. Interval | | P value |
|---|---|---|---|---|---|---|---|---|
| Gender | Female | 6.29 | 2.16 | 10.42 | 6.66 | -0.01 | 13.34 | 0.05 |
| Marital status | Married | 10.07 | 4.46 | 15.68 | 2.64 | -3.59 | 8.86 | 0.41 |
| | Divorced/ Widowed | 8.02 | 0.80 | 15.20 | -0.64 | -8.83 | 7.55 | 0.88 |
| Education | Can read and write | 0.73 | -4.82 | 6.40 | 2.64 | -2.62 | 7.89 | 0.32 |
| | Formal education | -9.34 | -13.86 | -4.38 | 0.03 | -5.35 | 5.41 | 0.99 |
| Occupation | Agricultural work | -3.88 | -8.93 | 1.16 | 3.62 | -3.81 | 11.04 | 0.34 |
| | Self employed | -3.61 | -10.29 | 3.08 | 2.33 | -3.85 | 8.50 | 0.46 |
| | other employments | -10.69 | -16.86 | -4.52 | -2.74 | -9.20 | 3.72 | 0.41 |
| | Unemployed | -14.79 | -32.99 | 3.42 | -4.20 | -20.62 | 12.23 | 0.62 |
| Live in the same house with patient | Yes | 13.33 | 7.98 | 18.69 | 5.07 | -0.62 | 10.77 | 0.08 |
| Time spent together | More than 32 hours per week | 6.76 | 1.72 | 11.81 | 2.16 | -2.66 | 6.99 | 0.38 |
| Relative wealth | medium and above | -8.38 | -12.46 | -4.30 | -2.20 | -6.20 | 1.80 | 0.28 |
| Relationship with patient | Sibling | 11.70 | 3.00 | 20.40 | 8.53 | 0.38 | 16.68 | 0.04 |
| | Child | 11.09 | 4.44 | 17.75 | 8.82 | 2.50 | 15.14 | 0.01 |
| | Spouse | 16.89 | 10.89 | 22.89 | 7.66 | 1.05 | 14.26 | 0.02 |
| | Parent | 18.63 | 12.07 | 25.20 | 10.60 | 3.46 | 17.73 | <0.01 |
| Total GHQ score | | 1.02 | 0.75 | 1.29 | 0.45 | 0.13 | 0.77 | 0.01 |
| Patient clinical characteristics | | | | | | | | |
| WHODAS Score | | 0.30 | 0.21 | 0.39 | 0.25 | 0.15 | 0.34 | <0.01 |
| Total BPRSE score | | 0.24 | 0.11 | 0.38 | 0.16 | 0.03 | 0.28 | 0.02 |

n=299 IEQ; Involvement evaluation questionnaire GHQ; General health questionnaire, WHODAS; World Health Organization disability assessment scale, BPRSE; Brief Psychiatric Rating Scale- Expanded version Note: References were: Male sex, Illiterate, house wife, single, not living in the same house, spent less than 32 hours per week and other family member

## DISCUSSION

To our knowledge, this is the largest and detailed examination of the subjective dimensions of care giving in any African country or any LMIC. The IEQ, although being used for the first time in Ethiopia, it has good psychometric properties. Its internal consistency was comparable, even better, than the report by the developers (3). The Cronbach's α for worrying, urging, tension and supervision reported by the developers was respectively 0.80, 0.71, 0.85 and 0.77 compared with 0.87, 0.86, 0.82 and 0.78 in the Sodo sample. The identified domains and factor structure are also consistent. These findings suggest that the measurement of these care burden constructs in this study was adequately robust.

The study demonstrates the enormous and consistent toll of caregiving in this setting. The overall pattern of burden is either comparable or worse than what has been reported in diverse income group countries. In a study of the burden of involvement in care using the IEQ among care givers of patients with schizophrenia in five sites in five

European countries (Amestrdam-The Netherlands, London-United Kingdom, Santander-Spain, Copenhagen-Denmark, and Verona-Italy) (21), the crude mean score ranged from 14.28 in the Copenhagen carers to 29.61 among the Verona carers. In terms of domain specific scores, urging and worrying had the highest score.

The score for urging ranged from 4.68 in the Copenhagen carers to 8.72 among the Verona carers. For worrying, the score was lowest for Amesterdam (5.75) and highest for Santander (12.78). The score in the Sodo sample is also higher than reports from other countries—both developing and developed (16,18,19,22).

Although most domains and items of care were highly endorsed, the leading areas of involvement of caregivers were around encouragement of self-care, and concern regarding general health, safety and future of patient. Interpersonal aspects of care and conflict were less prominent and care givers rarely wanted to abandon the patient. While the relatively high burden is likely to be in part due to the very high treatment gap (23) and the virtual absence of statutory social care system, the extended family network may have mitigated the extreme impact of caregiving.

Three broad factors, related to caregiver characteristics, type of relationship and patient characteristics were associated with caregiver burden. Being a female caregiver and experience of mental distress by the caregiver were the two caregiver characteristics associated with high burden score. All first-degree relations had higher IEQ score. More severe illness symptomatology and disability in the patient were the patient characteristics associated with higher IEQ score. All these factors; female sex (24-29), being a first degree relative (6,20,29,30), more severe symptomatology and disability (6,25,28,30-33); have all been found to be associated with increased care burden. While the consistency of the findings speaks to the validity of the findings in this setting, it also speaks to the need for improving access to care to reduce symptoms of illness and disability and to the need of identifying interventions that support female caregivers in particular. There is also scope for mobilizing the rich community resources and networks (23).

The findings of this study should be interpreted in the context of certain limitations. The study was cross-sectional, and direction of causality cannot be ascertained. Patients had no single diagnosis although over 80% of the sample had a diagnosis of schizophrenia spectrum disorder. However, in the context of primary care, which this study was focused on, a broad diagnosis is more appropriate. On the other hand, the population-based recruitment, the focus on primary care or integrated care, the relatively large sample size and the use of an instrument with robust characteristics make the findings meaningful, relevant and of interest.

***Conclusion***

In conclusion, the findings of the present study indicated that caregivers of persons with severe mental illness experience an elevated level of burden, particularly related to encouraging the patient and worrying about the patient. While caregivers in this study bear their 'burden' with little complaint, as shown in the low level of interpersonal tension with the patient, improving care provision to improve symptoms and disability in patients and mobilization of broader support should be considered urgent priority.

## ACKNOWLEDGMENT

I am grateful to my colleagues at PRIME Ethiopia, Addis Ababa University, who were instrumental in establishing a programme of interventions to address the huge mental health treatment gap in the Sodo district. The study reported here was part of the PRIME impact evaluation work. I would like to acknowledge the true partnership of the Sodo district, the health office and the community advisory board, and for their contribution to making healthcare available in their district. I am very grateful to my colleague, Ms. Rahel Berhane, for her indefatigable work coordinating the IDEAS project and carefully managing various data resources, including this carer burden data.

***Competing interest***

The authors declare that this manuscript was approved by all authors in its form and that no competing interest exists.

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