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Article

Burden of Care of Family Caregivers for People Diagnosed with Serious Mental Disorders in a Rural Health District in Kwa-Zulu-Natal, South Africa

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Abstract: An estimated 6% of the world population has serious mental illness, with one in four families having a member with some form of psychiatric disorder, who are mostly cared for by their relatives within a family setting. Although caregiving in a home setting is reported to be associated with significant mental distress, the burden of such distress is rarely measured. The purpose of this study was to quantify the burden of care among family caregivers of relatives with serious mental disorders, as well as to explore possible association between the caregiver burden of care and a range of caregiver and Mental Health Care User (MHCU) variables in a rural district in Kwa-Zulu Natal, South Africa. The Zarit Burden Interview (ZBI) scale was used to collect data from 357 caregivers, and STATA 14 was used to analyze data. The ages of the sample ranged from 18 to 65, with a mean of 50.29, and the majority (86%) were female and unemployed (83%). The ZBI scores ranged from 8 to 85, with a mean of 41.59. The majority (91%) tested positive for caregiver burden of care, which ranged from mild to severe. Using the Pearson Chi-square test of association (p=0.05), variables that were significantly associated with the burden of care were clinically related (caregiver self-reported depression, MHCU diagnosis, recent relapse of the MHCU), socio-economic (caregiver family monthly income, MHCU disability grant status and MHCU employment status) and socio-demographic (MHCU gender and MHCU level of education). The prevalence of burden of care is high and severe, and scarcity of resources in families and communities contribute to the high burden of care in these rural communities.

Keywords: Zarit Burden Interview scale; burden of care; home care giving; severe mental illness; rural setting.

Introduction

Mental disorders contribute to an estimated 14% of the global burden of diseases with the highest burden in developing countries **[1]**. The burden continues to impact negatively on the economic profile of affected countries, with resultant decline in productivity at both the national and individual levels, which is why they need national attention. While psychiatric conditions are responsible for little more than one percent of deaths globally, they account for almost 11% of the burden of disease **[2]**. Evidence of negative impact of mental disorders on the health and wellbeing of the caregivers continues to emerge, which is often reported to be worse in cases of depressive disorders or embarrassing behavior **[3,4].**

Among many African societies, caring for a family member who needs constant support, such as one who has chronic mental disorder, has been traditionally shared with other members, including extended families **[5],** which has been beneficial for both the caregivers and the person with chronic mental illness. However, changes in the social structures continue to shrink the extended family as it evolves towards the smaller nuclear families **[6]**. The relatively small nuclear families are left without financial and/or social support, thus becoming more vulnerable to unmanageable burden of care. This results in many caregivers carrying their physical, emotional, spiritual, and financial needs in solitude **[7],** as they miss out on the traditional family support networks.

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The COVID-19 pandemic has worsened the experiences of both the patients with mental illness and their caregivers. The pandemic has not only increased the global burden of communicable diseases, but has also presented long-term economic and social consequences, which has increased the prevalence of both depression and anxiety disorders. The COVID-19 impact indicators and shifting priorities of governments worldwide have substantially impacted on the mental health status of the world population, including the ability to care for family members at the household level. In particular, decreased social interactions, lockdowns, stay-at-home orders, decreased public transport, school and business closures, as well as subsequent loss of livelihood, loss of jobs and decreases in economic activity, have all negatively affected mental health of the world population. The pandemic has thus created an environment in which many determinants of mental health play out, which includes the caring of the mentally ill by their relatives at home, which remains a great concern **[8].**

South African legislation and policies that are intended to reduce psychosocial disability and promote mental health include the Mental Health Care Act no. 17 of 2002 (MHCA), the International Covenant on Economic, Social and Cultural Rights (ICESCR), as well as the African Charter on Human and People's Rights on the Rights of Persons with Disability in Africa. In South Africa, a significant portion of the budget for mental health services is traditionally used for in-patient care, leaving community or family-based care structures not funded **[9]**. Thus, the majority of people with mental illness who do not need in-patient care are being cared for in families and communities, but without the necessary financial support.

Although many families continue to provide care for their family members who have chronic mental illness, there is dearth of studies on quantifying the burden of care for such family members, as well as the impact of such burden on the carer's physical, psychological and social health. This is especially true in rural communities, where caring for the sick is commonly left to the family members **[10–12].** The purpose of this study was to quantify the burden of care among family members who provide care for their relatives with chronic mental disorders in rural UMkhanyakude District of Kwa Zulu Natal, South Africa.

Research Methodology

The Study Design

The study used a quantitative survey to determine the burden of care among family caregivers of people who were diagnosed with Psychotic (Schizophrenia Spectrum Disorders) and Mood (Major Depression and Bipolar) disorders.

Study Setting

The study was conducted in rural UMkhanyakude Health District, the second largest District in the Province of Kwa- Zulu Natal, with an estimated population of 625846. The District has 53 Primary Health Care facilities and a population of about 4 400 mental health care users in the patient registers of these Primary Health Care facilities. Because of this District's rural setting, many people walk long distances to access basic health services, including mental health care services. The study was conducted in 30 health facilities which were identified by their various hospital managers as having a high number of mental health care users who collect medication for mental illness on monthly basis.

Study Population

The study population consisted of primary caregivers of patients who live within the uMkhanyakudeHealth District, and receive care from health facilities on an outpatient basis.

Recruitment

The recruitment of the potential participants was done from identified health facilities, and individuals who were accompanying their relatives with mental disorders who came for health reviews and to collect their medication were recruited for the study. The inclusion criteria for the

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mental health care users were diagnosed with Schizophrenia, Major Depression or Bipolar Mood Disorder, and have been attending treatment in the district facilities for at least a year. The inclusion criteria for the family member or study participant was that they be 18 years or older, have been the primary caregiver for their mentally ill relative for at least a year, and be able and willing to provide informed consent.

Sampling Techniques

A purposeful and convenience sampling technique was used because all the participants were linked to their mentally ill relatives who were accessing services.

Sample Size

Using the Raosoft sample size calculator for a population of 4400 mental health care users registered in the health facilities of the district, a 5% margin of error, a confidence level of 95%, and aresponse rate of 50%, a minimum sample size of 354 was calculated. The final sample size was 357.

Data Collection Tools

i. The Zarit Burden Interview (ZBI) Scale was used to measure the burden of care among the participants. The ZBI is a globally validated tool which is designed for measuring caregiver's perceived burden of care while providing family care for a relative. The tool has been widely used in both developed and developing countries, and has been confirmed to be both reliable and valid [13–15].
ii. A quantitative questionnaire was used to collect socio-demographic data of the participants, as well as data on their relatives with mental disorders.

Data Collection

Data were collected by the researcher and a research assistant, who was trained in the methodology of data collection, ethics and protocols to adhere to prevention of the spread of the SARS virus.

Data collection occurred in an interview room of each facility. The purpose of the study was explained to the group of potential participants, and they were given the opportunity of asking questions or seeking clarifications. This was followed by the administration of the informed consent, which was followed by the administration of the socio demographic questionnaire, and lastly the ZBI scale.

To accommodate the limited literacy and numeracy skills of many of the participants, match-sticks were used to demonstrate the concept of the Likert Scale of the ZBI. A table of five columns was drawn, with each column representing how the participant felt with regards to the item displayed by their mental health care user relative, during their home caring process. The first column did not have a match stick (representing never or none), one match-stick represented rarely, two match sticks represented sometimes, three matches represented quite a bit, and four match sticks represented extremely.

The candidates were thanked and given a lunch pack as compensation for their time and participating in the study.

Ethical Considerations

The proposal received ethical approval from both the Sefako Makgatho Health Sciences University Research Ethics Committee, (SMUREC/H/111/2021: PG), and the KZN Provincial DOH Research Committee (KZ_202109-022). Permission to conduct the study was obtained from the UMkhanyakude Health District Research Committee, the sub-District Hospital Management Executive Officers, and the health facility Operation Managers of each participating facility. The individual participants provided informed consent.

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Data Analysis

The raw data was captured into the excel spreadsheet and uploaded into STATA version 14. The data of the caregivers and the patients were analysed separately. Socio-demographic data was descriptively analysed. The burden of care was determined by the scores of the ZBI scale, which has a maximum score of 88, with higher scores indicating heavier burden of care. The scores of the Zarit Burden Interview scale were used to categorize the total score of each participant as little or no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60) and extremely severe burden (61-88).The Pearson Chi-square test was used to explore the association between a range of socio-demographic variables and burden of care as measured by the ZBI; (p-value=0.05). Multivariate logistic regression was used to explore the association between the socio-demographic variables which were significantly associated with burden of care at chi-square test.

Characteristics of Caregivers

The mean age of the participants was 50.3, with the youngest being 18 years of age and the oldest caregiver at 65. The greatest proportion of the sample were female (n=306, 85.71%), single (n=192, 53.78%) and unemployed (n=301, 84.31 %). Almost all of the participants had daily contact (n=356, 99.72%) with the patient but only 15.97 % (n=57) reported receiving help with their caregiving duties. The average household monthly income of the participants was R3803.70. Further details are provided on Table 1 below:

Table 1. Characteristics of caregivers.

Variable	Frequency(n)	Percentage (%)
Age (n=357)		
≤40 years	77	21.57
41-60 years	185	51.82
≥61 years	95	26.61
Age (Mean 50.3; SD 12.2; Min 18; Max 65)		
Gender (n=357)		
Female	306	85.71
Male	51	14.29
Level of Education(n=357)		
No formal education.	99	27.73
Primary	110	30.81
Secondary	127	35.57
Tertiary	21	5.88
Marital status(n=357)		
Co-habiting	76	21.29
Married	80	22.41
Single	192	53.78
Widowed	9	2.52
Employment status(n=357)		
Employed	56	15.69
Unemployed	301	84.31
Religion (n=357)		
Christian	323	90.48
Nazareth	25	7.00
None	3	0.84
Other	6	1.68
Other Chronic Diseases (n=357)		

No	153	42.86
Yes	204	57.14
Self-reported depression (n=357)		
No	343	96.08
Yes	14	3.92
Number of children		
None	14	3.92
1-4 children	264	73.95
More than 5 children	79	22.13
Monthly family income		
Below 2000	146	40.90
R2001-R4000	147	41.18
R4000-R10 000	48	13.45
Above R10 000	16	4.48
Income (Mean R3803.70; SD 4217.45; Min R0; Max R39000)		
Relationship to patient		
Child	135	37.82
Parent	23	6.44
Sibling	85	23.81
Spouse	39	10.92
Other	75	21.01
Receiving help with caregiving (n=357)		
No	300	84.03
Yes	57	15.97
Living with patient (n=357)		
No	16	4.48
Yes	341	95.52
Other family members needing help (n=357)		
No	216	60.50
Yes	141	39.50
Number of days in contact with patient (n=357)		
Everyday	356	99.72
Occasional	1	0.28
Number of years as a caregiver		
Less than 5 years	83	23.25
6-10 years	91	25.49
More than 10 years	183	51.26
Caregiving years (Mean 14; SD 9.04; Min 1; Max 54)		

Socio-Demographic Information of MHCUs

The largest proportion of the patients were between the ages of 26-40 years (n=157, 43.98 %), male (n=245, 68.63 %) and were suffering from Schizophrenia (n=213, 59.66 %). Nearly all of the patients were unemployed (n=356, 99.72 %), with 77.31 % (n=276) of them receiving a disability grant. Table 2 below highlights further details of the socio-demographic variables.

Table 2. Socio-demographic information of participants.

Variable	Frequency	Percentage (%)
Age (n=357)		
Below 25 years	39	10.92
26-40 years	157	43.98

41-60 years	131	36.69
Above 60 years	30	8.40
Age (Mean 40.5; SD 12.6; Min 19; Max 76)		
Gender (n=357)		
Female	112	31.37
Male	245	68.63
Level of Education (n=357)		
No Education	62	17.37
Primary	130	36.41
Secondary	152	42.58
Tertiary	13	3.64
Marital status (n=357)		
Co-habiting	28	7.84
Married	16	4.48
Single	313	87.68
Diagnosis (n=357)		
Bipolar Mood Disorder	103	28.85
Major Depressive Disorder	41	11.48
Schizophrenia	213	59.66
Duration of illness (n=357)		
Less than 5 years	74	20.73
5-10 years	93	26.05
11-20 years	126	35.29
More than 20 years	64	17.93
Relapsed admission (n=357)		
No	299	83.75
Yes	58	16.25
Disability grant		
No	81	22.69
Yes	276	77.31
Employment status (n=357)		
Employed	1	0.28
Unemployed	356	99.72
Relationship to caregiver (n=357)		
Child	24	6.72
Other	75	21.01
Parent	135	37.82
Sibling	86	24.09
Spouse	37	10.36

Quantification of Caregiver Burden

The results showed that 89.37 % (n=320) of the caregivers were experiencing caregiver burden, with a mean ZBI score of 41.60 when a cut-off point of <21 was utlized. A majority of the participants were experiencing mild/moderate levels of burden (n=141, 39.50 %), followed by 35.01 %(n=125) that reported moderate/severe levels and 15.13% (n=54) experienced severe levels of caregiver burden. Figure 1 below show the prevalence of the caregiver burden and further illustrate the findings.

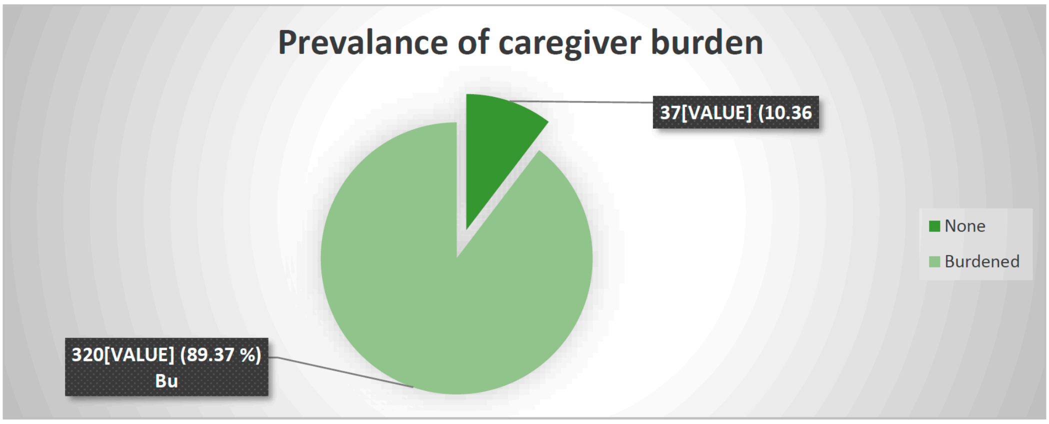

Figure 1. Prevalence of caregiver burden.

The heaviness of the burden of care ranged between little to severe, as shown in Figure 2 below

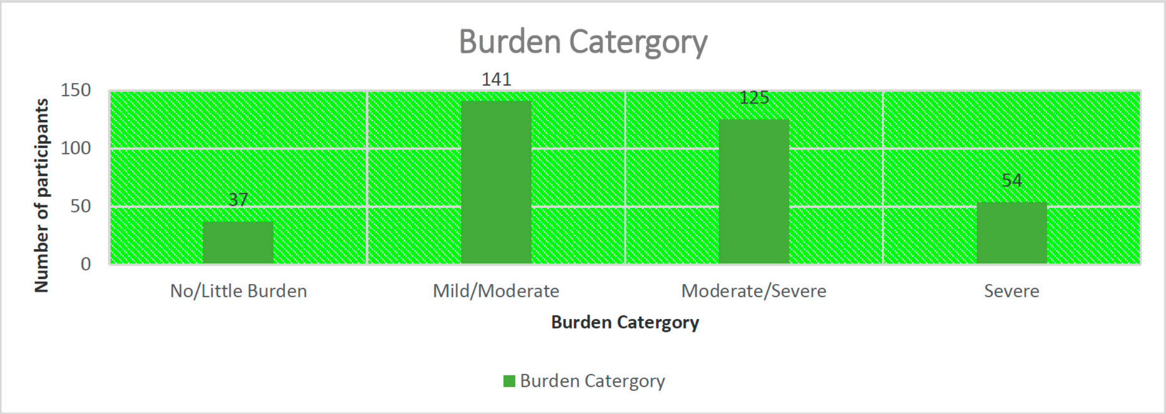

Figure 2. The levels of burden of care.

Factors Associated with Caregiving Burden

The Pearson chi-square test of association showed that there were seven main factors that were associated to caregiving burden. Three of those factors were directly related to demographic variables of the caregiver, i.e. age, help received with caregiving role and self-reported depression (p-value=0.05). The other three factors were related to employment status, gender and the relapsed admission history of the mental health patient (p=0.05). The remaining factor was related to the monthly household income (p-value=0.05).

Table 3. Factors associated to caregiving burden.

Factors	Frequency (%)	Burdened (%)	Not Burdened (%)	Chi^2	p-value
Age of Caregiver				**10.1653**	**0.006**
≤40 years	77 (21.57)	65 (20.31)	12 (32.43)		
41-60 years	185 (51.82)	175 (54.69)	10 (27.03)		
≥61 years	95 (26.61)	80(25.00)	15 (40.54)		
Monthly family income				**20.6410**	**0.000**
Below 2000	146 (40.90)	139(43.44)	7 (18.92)		
R2001-R4000	147 (41.18)	133 (41.56)	14 (37.84)		
R4000-R10 000	48 (13.45)	35 (10.94)	13 (35.14)		
Above R10 000	16 (4.48)	13 (4.06)	3 (8.11)		

Self-reported depression of caregiver				**5.1997**	**0.023**
No	343 (96.08)	310 (96.88)	10 (3.13)		
Yes	14 (3.92)	33 (89.19)	4 (10.81)		
Receiving help with caregiving role				**5.8278**	**0.016**
No	300 (84.03)	274 (85.63)	46 (14.37)		
Yes	57 (15.97)	26 (70.27)	11 (29.73)		
Gender of the patient				**4.0719**	**0.044**
Female	112 (31.37)	95 (29.69)	17 (45.95)		
Male	245 (68.63)	225 (70.31)	20 (54.05)		
History of relapsed after admission				**5.5647**	**0.018**
No	299 (83.75)	263 (82.19)	36 (97.30)		
Yes	58 (16.25)	57 (17.81)	1 (2.70)		
Employment status of MHCU				**8.6729**	**0.003**
Employed	1 (0.28)	0 (0.00)	1 (2.70)		
Unemployed	356 (99.72)	320 (100.00)	36 (97.30)		

At multivariate logistic regression, only monthly family income and relapsed after admission remained statistically significant, as shown on Table 4 below:

Table 4. Multivariate analysis .

Factors	Coef.	Std. Err.	P>|z|	[95% Conf. Interval]	
Age of Caregiver	.0204188	.2593118	0.937	-.487823	.5286606
Monthly family income	-.7151498	.2243773	0.001	-1.154921	-.2753784
Self-reported depression of caregiver	-1.225815	.6799649	0.071	-2.558521	.106892
Receiving help with caregiving role	-.2534951	.4568942	0.579	-1.148991	.6420011
Gender of the patient	.5283181	.3777569	0.162	-.2120719	1.268708
Relapsed admission patient history	2.248435	1.056517	0.033	.1776989	4.31917

Discussion

The finding that most family caregivers were female was previously reported in other studies, where caregiving responsibilities were assumed mostly by females **[5,14]**, and that the burden of care was higher among females **[22].** This suggests that female caregivers need additional resources to support their mental health, such as social support as well as psycho-educational support.

The current study found that males were more affected by psychotic and mood disorders, which are aligned with other studies which reported that Major Depression and Schizophrenia Spectrum Disorders were more prevalent among males **[19],** and they were the ones mostly looked after by females. These findings concur with some Sub-Saran studies done on the burden of care in general and mental health care specifically, which reported that males were mostly affected by serious mental illness, especially in the Psychotic Spectrum range **[20,21].** This suggests that a focus on screening for these disorders among men should be strategically integrated into men's health services.

Of interest to this research was the "cohabiting group" of the caregivers; n=76 (21%), whose roles are supposed to be the same as the married group because they live with their partners permanently although not officially married, which suggests limited commitment. This group formed a fourth of the sample and its marital status, under trying circumstances, can jeopardize the quality of care and dedication, to be given to the supposedly mental health care user spouses or partners. This cohabiting concept had no literature support and its subsequent impact on home caring of mental health care users. Noticeably, the significant majority (88%, n=313) of the mental health care users were found

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to be single, which is similar to other studies which reported the same, i.e. most people with mental disorders are single **[22,23].** This can be explained by the difficult social situations experienced by people with mental disorders, which render them unable to form and maintain social relationships, as well as the stigma perpetrated against mental illness and people so affected **[24].** In the current study, marital status for either caregivers or their mental health care user relatives was perceived by caregivers as not contributing significantly to their burden of care.

The majority (83%, n=301) of the caregivers in the current study were unemployed, which confirms the high unemployment rates in South Africa **[25,26],** especially among Black Africans **[27],** who live in rural areas **[28]**. Some caregivers had to quit their jobs in order to fully take care of their mentally ill relatives. This concurs with findings from both developed and developing world, which reported that family caregivers were often compelled by circumstances and demands to care for their mentally ill relatives, to the extent that they often have to quit their jobs in order to offer full time care, despite the poverty this decision could expose them to **[29–31],**. Moreover, it helps to improve the morale of the caregiver if the mental health care user is employed because relatives believe that if the mentally ill person has a job, it suggests that he/she is being cured of his mental condition, as well as improving his/her dignity and self-esteem **[1].** In this study, most of the unemployed mental health care users (77%, n=276) depended on Government disability grant. These social grants contribute significantly towards the family monthly income, thus improving the socio-economic status of the family **[5].**

Only a few participants, (4%, n=14) reported that they were depressed because of caring for their mental health care user relatives, which proved to be statistically significant and therefore contributing a great deal towards their burden of care. This finding concurs with the Asian study **[32],** which reported that depression could affect caregivers of their mental health care user relatives in two ways, i.e. either easing their burden of care or the burden increasing depressive symptoms they already exhibit during the caring process.

The results of the current study showed that almost half the sample had been primary caregivers for long periods of between eleven and thirty years during which time they were living with the family member being cared for, almost every day. This situation statistically proved not to be significant as far as family member caregiver burden was concerned. Literature acknowledges the family support impacting positively on the quality of care given to the mental health care user relative, within the family context **[33,34].**

With the context of the family dynamics of the Zulu culture, the relationship between carer and MHCU does not mean much because it is not only the close family member but also the extended family member, who comes to the party of caring if the worse comes to the worst. These family dynamics differ from those from developed countries, where the nuclear family does not necessarily embrace the extended family members **[22,35].**

The sample had fewer MHCU who were diagnosed with Major Depression, which contrasts with global trends. This may be explained by previous findings that in comparison with data from other countries, South Africa has lower rates of Major Depression **[36].** But it may also be explained by under diagnosis and under reporting of depression, which was reported to be up to 87% in developing countries **[37]**. Either way, the need for financial and human resources for diagnosing, treating and managing depression remains high, with the ratio of psychiatrist to a given population being unfavourable **[38,39].** Moreover, major depression is not readily diagnosed because it is mostly limited to the experience of the patient, whereas the destruction and dramatic acts displayed by patients with Schizophrenia and Bipolar Mood Disorder with Manic episode, add more burden to the attention of society and is apparent to the burden of the caregiver **[40].** Although most of the MHCUs had not experienced recent relapses, relapse had more negative impact on the mental health of the caregiver, and was therefore statistically associated

Conclusions

Although the difficulties experienced by family caregivers of MHCUs have been reported **[41]**, this study specifically quantified the burden of care, which integrated not only the mental aspects,

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but a comprehensive burden that includes other aspects like finances, access to additional assistive resources, and other responsibilities that are on the shoulders of the caregivers. The study findings therefore conclude that the mental distress of the caregivers is acknowledged and what all studies agree with is that MHCUs need additional resources to adequately attend to their needs, and so reduce the burden of the caregivers.

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Recommendations: In the context of high burden of care for the family caregivers, it is recommended that mental health professionals at primary health care level must align their service delivery plans with identification of the needs of the family caregivers, and refer these to social services, which can benefit the MHCU. It is further recommended that screening for mental disorders, especially the psychotic spectrum range, should be integrated into health services at primary health care level. Without attending to this important aspect of community-based care, the treatment outcomes of MHCUs will remain negative. Acknowledging the extensive mental health impact of the Covid-19 pandemic on society, there is a need to incorporate the mental health impacts thereof in the broader health care services.

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