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Impact of incentivizing ASHAs on the outcome of persons with severe mental illness in a rural South Indian community amidst the COVID-19 pandemic

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ABSTRACT

Background & objectives: Task shifting has been recommended as a strategy to reach out to persons with mental illness and bridge the treatment gap. There is a need to explore task-shifting using existing health staff like Accredited Social Health Activists (ASHAs). We examined the impact of incentivizing ASHAs on the outcome of persons with severe mental illness (SMI) amidst the pandemic.
Methods: One hundred eighty-four adults with SMI from Jagaluru taluk were enrolled and followed up for a year. They were assessed for disability, work performance, internalized stigma, and illness severity at baseline, six months, and 12 months follow-up. ASHA workers were incentivized to ensure follow-up consultations, address concerns regarding illness/ medication side effects and monitor medication adherence.
Results: Out of the 184 recruited patients, 7 died (non-COVID-19 causes), 22 stopped treatment and did not report for follow-up consultations, 11 shifted to treatment from other centers, and in 1 case, there was a change in diagnosis. 143 (78%) patients with SMI completed the study amidst the COVID-19 pandemic. At one year follow-up, there was a significant reduction in disability, illness severity, self-stigma, and improved work performance.
Conclusion: Incentivization of ASHAs helped ensure continuity of care to persons with SMI despite lockdowns and COVID-19 exigencies. It is feasible to involve ASHAs in the treatment of persons with SMI.

1. Introduction

According to the National Mental health survey, 2015–16 of India, more than 70% of the Indian population lives in rural areas with limited awareness of mental illness and limited availability, accessibility, and affordability of mental health services (Gururaj et al., 2016). In India, schizophrenia and bipolar affective disorders (called severe mental illnesses; SMI) are leading causes of years lived with disability (YLDs) (Collins et al., 2011; Sagar et al., 2020). The treatment gap for schizophrenia, other psychotic disorders, and bipolar affective disorders is as high as 75.5% and 70.4%, respectively (Gururaj et al., 2016).

Major barriers to addressing the treatment gap are scarcity of trained human resources, inequitable and inefficient resource distribution and utilization, poverty, social deprivation, poor community awareness, and stigma associated with mental illness (Purgato et al., 2020). To address this, task shifting (also known as task sharing), defined as "delegating tasks to existing or new cadres with either less training or narrowly tailored training," has been advised (Purgato et al., 2020; Ginneken et al., 2021; Kakuma et al., 2011). Task shifting may involve primary care health workers who have received general health training and community workers with no background health training (Purgato et al., 2020). Treatment from primary care health workers alone or in collaboration with mental health specialists improves day to day functioning of adults with SMI (Ginneken et al., 2021).

The 12th five-year plan of the district mental health program (DMHP) speaks about a cadre of 'community mental health workers' who are local residents with ten years of schooling and will be offered an honorarium for their services (Policy Group, 2012). This cadre is not

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functioning in any of the DMHPs to date. Task-shifting with the help of Accredited Social Health Activists (ASHAs) is a feasible and effective strategy to reach out to persons with severe mental illness (SMI) in the community and address the treatment gap (Sivakumar et al., 2022a; Sivakumar et al., 2022b). If adequately supported, ASHAs can fulfill the role of community mental health workers for persons with SMI with little additional burden on their existing duties (Sivakumar et al., 2022b).

ASHAs are honorary, literate female primary health workers who offer multiple maternal and child health services for an honorarium (Sivakumar et al., 2022b). ASHAs are not paid an honorarium for working with persons with mental illness (Sivakumar et al., 2022b). Incentivizing ASHAs to offer services to persons with SMI is likely to improve the outcomes (Sivakumar et al., 2022b).

We planned a randomized control trial examining the effect of incentivizing ASHAs to deliver community-based rehabilitation interventions to persons with SMI. PHCs in the Taluk were randomized to implement intervention through ASHAs who were incentivized or to function as usual – in the latter group, volunteers from an NGO working for persons with disability were expected to provide their services as usual. However, due to the COVID-19 pandemic, the trial could not be conducted as planned (Sivakumar et al., 2022a). Instead, we incentivized all ASHAs to ensure follow-up consultations, address illness/ medication side effects concerns, and monitor medication adherence. This paper describes the impact of incentivizing ASHAs on the outcome for persons with SMI.

2. Methodology

2.1. Setting

The study was conducted in Jagaluru, a taluk (an administrative block) of Davangere District, Karnataka State, India. The taluk has 10 Primary Health Centres (PHCs) and 1 Taluk hospital. As part of ongoing CBR program, free mental health camps have been conducted fortnightly on Tuesdays at PHCs & the taluk hospital since August 2015 in partnership with the Government of Karnataka and NGOs. More details about Jagaluru taluk and the CBR program are described elsewhere (Sivakumar et al., 2020).

2.2. Sample

For the study, SMI was operationally defined as schizophrenia spectrum disorders (F20–29) and bipolar affective disorders (F31) as per the international classification of diseases (ICD-10). Adults with SMI residing in the taluk, availing of treatment from the Jagaluru CBR program at PHC/ taluk hospital, and consenting to participate in the trial were included in the study from November 2019 to September 2020. The duration of the intervention was a minimum of one year for each person with SMI.

2.3. Intervention

As part of the Jagaluru CBR program, we have trained ASHAs to identify persons with SMI from their villages and refer them for treatment. The ASHAs were trained for 90 min by a psychiatrist in the local language about symptoms, course, outcome, and treatment of SMI, followed by an interactive session where queries were clarified. ASHAs were encouraged to refer patients to nearby PHC or taluk hospital for consultation.

This was followed by on-the-job training. ASHAs accompanied patients for evaluation. Patients were interviewed, and treatment was initiated in the presence of ASHAs who were requested to supervise treatment and ensure follow-up. ASHAs would observe the psychiatrist assess and educate patients and their family members about their illness, explain the side-effects of medications (if any), and the need for continued care, including engaging in constructive activities as part of patients' recovery. On-the-job training differed among ASHAs based on the number of patients referred. A social worker from the team was available to ASHAs for guidance over the phone.

As part of the present study, we incentivized the ASHAs by Rupees 150 [2 US Dollars (1 US Dollar= Rupees 75)] to ensure follow-up consultations are scheduled once in three months for persons with SMI from the respective villages. The ASHAs informed persons with SMI about scheduled consultations and accompanied them for consultations when possible. During home visits, ASHAs inquired about the patient's clinical status from family, addressed concerns related to illness/ medication side effects, and advised the family about the importance of medication adherence.

The institutional ethics committee approved the protocol and was updated about protocol deviations due to the COVID-19 pandemic. The study was registered in Clinical Trials Registry India (CTRI) CTRI/2019/08/020585 dated 6th August 2019.

2.4. Assessment tools

1. Socio-demographic proforma: A semi-structured proforma was developed for the study to collect the socio-demographic information of the patient and family members.
2. Indian Disability Evaluation and Assessment Scale (IDEAS) (Ministry of Social Justice and Empowerment, 2018): The IDEAS was originally developed for measuring and certifying disability due to mental illness in India. It assesses disability across four domains: self-care, interpersonal relationships, communication and understanding, and work. The total score is added with the duration of illness score to give a global score. IDEAS has good face validity, criterion validity, and internal consistency.
3. World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) (Üstün et al., 2010). WHODAS 2.0 was developed synchronously with the international classification of functioning (ICF) to measure health status and disability across different cultures and settings. It can measure disability across all diseases, including mental and substance use disorders. The instrument was developed through an international collaborative approach and had excellent psychometric properties. We used the 12-item interviewer-administered questionnaire translated into Kannada for this study.
4. CGI-SCH (Haro et al., 2003) and CGI-BP (Spearing et al., 1997). The clinical global impressions scale (CGI) was modified to assess global illness severity and change in schizophrenia and bipolar disorder patients. CGI-SCH rates the severity of illness over the last one week and degree of change compared to a previous evaluation in positive, negative, depressive, cognitive symptoms, and overall severity (Haro et al., 2003). It is a simple, valid, reliable instrument to evaluate severity and treatment response in schizophrenia (Haro et al., 2003). CGI-BP can be used for acute and prophylactic assessments of the severity of illness, change from the preceding phase, and change from the worst phase of illness (Spearing et al., 1997). The investigators have obtained permission from the authors for use in studies.
5. Internalized stigma of mental illness (ISMI) scale (Boyd et al., 2014). The ISMI contains 29 items producing five subscales (alienation, stereotype endorsement, discrimination experience, social withdrawal, stigma resistance) and a total score. The scale has good psychometric properties across various languages, cultures, conditions, and situations. The investigators have obtained permission from the authors for translation into Kannada and use them in studies.

The assessments were done at baseline, six months follow-up, and 12 months follow-up. The patient, caregiver, and ASHAs were interviewed for the assessments. The first author did the IDEAS, CGI-Schiz and CGI-

BP assessments. The first author trained the project staff who did the WHO-DAS and ISMI assessments.

2.5. Statistical methods

Descriptive statistics were used to describe study participants' socio-demographic and clinical variables. Friedman's test compared variables across baseline, six-month, and 12-month follow-ups. SPSS version 28 was used for data analysis.

3. Results

Table 1 depicts the baseline characteristics of participants. The average duration of illness was 11 years. Most patients were married.

143 (78%) patients with SMI followed up at the end of 12 months amidst the COVID-19 pandemic.

Table 2 depicts the statistically significant improvement in disability, illness severity, work functioning, and self-stigma from baseline to 12-month follow-ups.

4. Discussion

The patients were chosen from the Jagaluru cohort, which we have followed up with since 2015. The cohort had a low level of illness severity as most of them were on regular medications and had mild disability. Most patients with schizophrenia spectrum disorder were on either risperidone, olanzapine, or injection fluphenazine depot. Three patients were on clozapine. Patients with bipolar affective disorder were on valproate, lithium, carbamazepine, or olanzapine as mood stabilizers.

Only one patient refused consent for the proposed intervention by ASHAs. This indicates a high level of acceptability of ASHA intervention. As the patient was an unmarried female, the family did not want ASHA or others in the locality to know about her illness as they felt it would affect her marital prospects. The family would come and avail treatment from a different PHC far from their residence.

78% (143/ 184) of persons with SMI recruited for the study completed the one-year follow-up. Out of the 184 recruited patients, 7 died (non-COVID19 causes), 22 stopped treatment, 11 shifted to treatment from other centers, and in 1 case, there was a change in diagnosis. Twenty-two persons with SMI had stopped medications as they were feeling fine and did not see the need to continue treatment. Usually, such patients consult us when the symptoms recur.

Table 1
Socio-demographic variables of the participants.

Socio-demographic variables	Total population (n = 184) Mean (S.D.)/ frequency (%)	Schizophrenia spectrum disorders (N = 138) Mean (S.D.)/ frequency (%)	Bipolar Disorder (N = 46) Mean (S.D.)/ frequency (%)
1. Age (years)	47.22 (13.38)	46.56 (13.26)	49 (13.67)
2. Gender (Male: Female)	78:106 (58% females)	52:86 (62% females)	26:20 (43% females)
3. Duration of Illness (in years)	11.21 (7.18)	10.4 (6.72)	13.6 (8.01)
4. Income per annum (in US Dollars) ($1 = Rs. 75)	$ 834.92 (912.33)	$ 818.13 (977.98)	$ 882.01 (704.57)
5. Marital Status			
a. **Married**	113 (61%)	80 (58%)	33 (72%)
a. **Separated/ Divorced**	16 (8%)	14 (10%)	2 (4%)
c. Single	33 (18%)	26 (19%)	7 (15%)
d. Widowed	21 (11%)	17 (12%)	4 (9%)
6. Years of Education	4.64 (4.88)	4.7 (4.95)	4.22 (4.72)

Table 2
Comparison of scores across time: Friedman's Test.

Variables	Timepoint			Test statistic	p-value
	Baseline	**1st follow-up**	**2nd follow-up**		
	Median (inter-quartile range) Mean ± SD				
WHO-DAS (n = 143)	16 (12-32) 28.58 ± 26.15	13 (12-17) 20.08 ± 20.90	12 (12-15) 18.55 ± 18.18	107.14#	0.001
IDEAS (n = 123)	5 (3-7) 5.86 ± 3.86	4 (3-5) 5.11 ± 3.33	4 (3-5) 4.85 ± 2.85	23.21#	0.001
ISMI (n = 136)	1.60 (1.24-2.27) 1.79 ± 0.66	1.48 (1.15-2.04) 1.65 ± 0.60	1.21 (1.07-1.56) 1.37 ± 0.44	115.42#@	0.001
IDEAS-work (n = 123)	1 (0-2) 1.1 ± 1.24	0 (0-1) 0.93 ± 1.21	0 (0-1) 0.76 ± 1.12	27.56@	0.001
CGI-schiz overall severity of illness (n = 99)	1 (1-3) 1.82 ± 1.23	1 (1-2) 1.68 ± 1.09	1(1-2) 1.49 ± 0.94	11.18@	0.001
CGI-BP overall severity of illness (n = 31)	1 (1-1) 1.39 ± 0.99	1 (1-1) 1.29 ± 1.04	1(1-1) 1.1 ± 0.7	7.118@	0.028

@ post-hoc comparisons.
# $p < 0.05$ for comparison of baseline with the first and second follow-up assessment
@ $p < 0.05$ for comparison of the first follow-up assessment with the second follow-up assessment

The study was conducted amidst the COVID-19 pandemic. Continuity of care was ensured with the help of telepsychiatry and ASHAs during the COVID-19 lockdowns (Sivakumar et al., 2022a). Treatment with antipsychotics and psychoeducation alone has been shown to favorably influence the course of schizophrenia and reduce disability in a substantial proportion of patients from rural communities (Kumar et al., 2017). As ASHAs live in the same community, they could psychoeducate families, monitor medication adherence, identify early signs of relapse, contact treating psychiatrists and initiate remedial measures. They were also better positioned to cater to the health needs of persons with SMI through referrals to the government health system. During COVID-19 lockdowns, the patients could not travel for the consultations, and there was a risk of medication default leading to relapse. During such a situation, ASHAs took part in teleconsultations with the treating psychiatrist from respective PHCs. ASHAs updated the status of the patients, collected medications from the hospital, and gave it to patients at their homes (Sivakumar et al., 2022a). These interventions likely had a cascading effect on the clinical stability of the person with SMI resulting in better functioning.

The ASHAs were receptive to mental health issues as they saw the change in the lives of families of persons with SMI in their community. They were also empowered and seen as 'agents of change' in the local community (James et al., 2019). As residents of the same community, their expertise will remain in the same community, continuing to benefit it. We believe that the local community also supported people with SMI helping in community reintegration and reducing internalized stigma (Sivakumar et al., 2022a).

ASHAs helped ensure continuity of care for persons with SMI in Jagaluru amidst the COVID-19 pandemic. The rapport and collaboration with ASHAs built over the years in the CBR program ensured that care was available when needed. It is well known that continuity of mental health care, particularly for persons with SMI, was disrupted during the lockdowns and travel restrictions in the context of the pandemic. This

was not the case in this community, thanks mainly to the service rendered by the ASHAs. We believe that the incentivization of ASHAs helped ensure continuity of care for persons with SMI. ASHAs can be involved in mental health service delivery, and methods of recognizing and incentivizing their services should be explored.

4.1. Limitations

Due to COVID-19 related work, ASHAs could not regularly accompany patients for consultations. Due to COVID-19 exigencies, the originally proposed randomized controlled trial could not be carried out; only medication adherence could be ensured, and other community-based rehabilitation interventions could not be implemented.

The same raters did the assessments over time.

4.2. Future directions

The cost-effectiveness of ASHAs delivered interventions for persons with SMI needs to be studied prospectively in a randomized controlled study.

5. Conclusion

Incentivization of ASHAs helped us ensure continuity of care to persons with SMI despite lockdowns and COVID-19 exigencies. It is feasible to involve ASHAs in the treatment of persons with SMI.

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Conflict of Interest

None.

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Author contribution

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

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