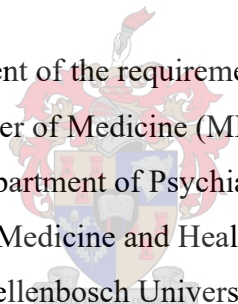


Long-term outcomes of an assertive community treatment (ACT) intervention: a 10-year follow-up

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Declaration

By submitting this thesis, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

This dissertation includes an extended literature review and a publication-ready manuscript. The development and writing of the papers (published and unpublished) were the principal responsibility of myself and, for each of the cases where this is not the case, a declaration is included in the dissertation indicating the nature and extent of the contributions of co-authors.

Signed: Danell Coetzee

Date: 29/3/2021

List of Abbreviations:

ACT	Assertive Community Treatment
HICs	High-income countries
HFU	High frequency user
PSR	Psychosocial rehabilitation
SD	Standard deviation

Table of Contents

Extended literature review	1
References:	5
Full author details	9
Corresponding author	9
Abstract.....	10
Introduction	11
Methods	13
Study design	13
Study setting	13
Study sample.....	14
Data collection	14
Data analysis.....	15
Ethical considerations	15
Results	15
Discussion.....	18
Conclusion	21
Acknowledgements.....	22
Funding.....	22
Conflict of interest	22
Author contributions	22
References:	23

Extended literature review

Deinstitutionalization refers to the movement of mental health care users from inpatient facilities to community care.¹ It can be broken down into three principal components: downsizing of psychiatric hospitals; diversion of patients from hospital admission; and finally, the provision of community-based services.¹ High income countries (HICs) started the process of deinstitutionalization of mental health patients during the 1950s.² The initial aim was to improve the overall quality of care for psychiatric patients, but the process was not without challenges.

In South Africa, deinstitutionalization of mental-health care patients started in the 1990s. As was the case in other lower resourced settings, the decrease in inpatient beds in South Africa was unfortunately not followed by strengthening of outpatient or community-based services.³ The increased pressure on the availability of inpatient beds resulted in the premature discharge of mental health patients to accommodate only those with severe illness.³ Consequently, this practice exacerbated what we call the “revolving door phenomenon”, where patients are admitted to hospital multiple times, stay only a short time, and are discharged before they are fully recovered.⁴⁻⁶ To address the pressure on inpatient facilities following deinstitutionalization, a variety of outpatient services have been implemented. These services include day clinics, drop-in centres, step-up and step-down facilities and assertive community treatment (ACT).

Following its development by Stein and Test in the 1980s, ACT gained ground as a popular intervention in HICs.⁷ ACT is an outpatient treatment approach where patients are assigned to a specific keyworker (a caseworker in ACT is referred to as a keyworker) who oversees and closely monitors the treatment of their assigned patients. The core features of ACT consist of small caseloads, access to 24-hour care, a multi-disciplinary approach, regular meetings, careful

monitoring of medication, and individualized care. It is a well-researched psychiatric treatment intervention and has been implemented in many countries around the world, including South Africa.^{8,9}

The effectiveness of the ACT intervention has been extensively studied in HICs, with studies reporting both a reduction in hospital inpatient days, fewer emergency room visits, improved quality of life and level of functioning, and increased patient satisfaction.¹⁰⁻¹⁵ While ACT resulted in higher outpatient costs, the approach was still seen as a cost-effective option given that a reduced number of admission days resulted in a total reduction in yearly patient costs.¹² Another important finding was that these positive outcomes, related to psychosocial functioning, quality of life and treatment compliance were substantial for individuals who received ACT over longer periods.^{15,16} In these studies, it was found that ACT is the preferred treatment approach over other community-based treatment options for both the treating staff and the patients.¹¹⁻¹⁵

However, there is an ongoing discourse regarding the effectiveness of ACT, given the varying degrees of success reported in the literature. Initial positive outcomes relating to reduction in admission days found in studies from the United States of America in the 1990s could not be replicated in two large United Kingdom (UK) studies.¹⁰ The UK studies (namely UK700 trial and PRISM trial) found no reduction in hospitalization rate in groups receiving ACT versus standard care.¹⁷⁻¹⁹ These conflicting findings cast doubt on the notion of the cost-effectiveness of ACT as a psychiatric treatment intervention.

To elucidate the factors that could have contributed to poor outcomes, Burns et al. (2010) conducted a meta-analysis which included 64 studies on ACT.⁸ The authors reported that many studies failed to properly define their control group, with many of the core ACT features

implemented as part of standard care, such as frequency of visits and home visits. Burns also concluded that ‘standard care’ may differ between settings. Other studies have also suggested that the positive outcomes of community-based interventions, including ACT, would be more pronounced in settings where standard care is less comprehensive.^{5,20,21}

Fewer studies have been done on the effectiveness of ACT interventions in lower resourced settings. A pilot study by Odenwald et al. (2012) in Somalia found that despite the resource-poor conditions, a community-based outpatient mental health service was feasible and well accepted.²² A recent review assessing community-based interventions for schizophrenia in lower-to-middle-income countries concluded that even though limited evidence exists for the effectiveness of community-based psychosocial interventions in lower resourced settings, these interventions should still be provided in addition to facility-based care.²⁰

In South Africa, the first ACT intervention was implemented in the Western Cape, South Africa in 2007, at three Psychiatric Hospitals: Lentegeur, Valkenburg & Stikland Hospital. This was an attempt to strengthen the outpatient services and to decrease re-admission rates of high frequency users. The intervention was implemented as a modified ACT program by way of a randomized control trial. Patients meeting pre-defined high frequency user (HFU) criteria, were randomly assigned to either the modified ACT intervention, or standard care. The intervention differed from standard ACT treatments by allowing for bigger caseloads and less frequent visits. After hour services were available via the standard on-call service.⁴

At one year follow-up it was demonstrated that focussing on maintaining adherence to treatment and offering additional support did not only reduce inpatient days but also improved psychopathology in patients with severe mental illness.⁹ A longitudinal study including the same study participants after three years of treatment found that assertive interventions can be

successfully modified in under-resourced settings and sustain reductions in in-patient usage over time, while remaining affordable and feasible within the context of a developing country.²³ To date, there are no long-term studies focussing on the outcomes of ACT interventions in lower resourced settings.

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Abstract

Background: Assertive community treatment (ACT) is an intervention implemented in many countries to manage the effects of deinstitutionalization, with studies in South Africa demonstrating decreased admissions at 12 and 36-month follow-up for patients receiving modified ACT compared to standard care. Whilst shown to be effective, costs associated with the intervention has raised the question of its feasibility in developing countries.

Aim: This study aimed to describe the demographic and clinical outcomes of a group of patients included in an ACT interventional study, 10 years after inclusion.

Methods: This is a retrospective description of the 10-year outcomes of a group of 55 high-frequency psychiatric users (HFUs) included in the first ACT intervention in South Africa. The group either received follow-up with a modified ACT program or at a community care centre. Demographics, admissions, social functioning and adverse events were outcomes reviewed.

Results: Nine patients remained in ACT for the full 10 years, 16 were never included and 30 patients spent some time in ACT. Five participants died, 2 were admitted to long-term wards and 12 were never re-admitted. The group had an overall low level of education, a mean age of 43 years and most were single (82%). The mean number of admissions were 3.73 and the mean number of admission days was 261.11.

Conclusions: This was the first study looking at the long-term outcomes of a group of HFUs in an under-resourced setting receiving a modified ACT intervention. Correlation with the poor psychosocial outcomes often associated with schizophrenia were found in this group, but overall, the study findings suggest increased stabilization, service utilization and quality of life for patients exposed to ACT at some stage in their treatment.

Introduction

Deinstitutionalization refers to the movement of mental health care users from inpatient facilities to community care.¹ In South Africa, deinstitutionalization caused significant pressure on mental health services as the drastic reduction in the number of inpatient beds happened without providing sufficient community-based placements and resources to address the needs of mental health care users.² Bed pressures in psychiatric facilities have led to the emergence of premature discharge policies where patients are discharged before they have fully recovered. This has exacerbated the “revolving door phenomenon” where patients are admitted to hospital multiple times, stay for only a short time, and are prematurely discharged.^{3,4} To address the pressure on inpatient facilities following deinstitutionalization, a number of outpatient interventions have been implemented.

Assertive community treatment (ACT) is an established team-based outpatient treatment intervention. Patients are assigned to a specific keyworker who oversees and closely monitors their treatment, with support from a multi-disciplinary team. The core features of ACT are small caseloads, access to 24-hour care, a multi-disciplinary approach, regular meetings, careful monitoring of medication and individualized care.⁵ ACT has been implemented in many countries to both support patients in the community and reduce re-admission rates.⁶

The effectiveness of the ACT intervention has been extensively studied in high-income countries (HICs), with initial studies reporting both a reduction in hospital inpatient days as well as improved patient satisfaction.⁷ A study done in the Netherlands on a flexible ACT intervention concluded that the longer the duration of ACT the better the outcomes.⁸ These improved outcomes related to psychosocial functioning, quality of life and treatment compliance.

However, there is an ongoing discourse regarding the effectiveness of ACT, given the varying degrees of success reported in the literature. Initial positive outcomes relating to reduction in admission days found in studies from the United States of America in the 1990s could not be replicated in two large United Kingdom (UK) studies.⁷ The UK studies (namely UK700 trial and PRISM trial) found no reduction in hospitalization rate in groups receiving ACT versus standard care.⁹⁻¹¹ These conflicting findings cast doubt on the notion of the cost-effectiveness of ACT as a psychiatric treatment intervention. To elucidate the factors that could have contributed to poor outcomes, Burns et al. (2010) conducted a meta-analysis which included 64 studies on ACT.⁶ The authors reported that many studies failed to properly define their control group, with many of the core ACT features implemented as part of standard care. Other studies have also suggested that the positive outcomes of community-based interventions, including ACT, would be more pronounced in settings where standard care is less comprehensive.^{3,12,13}

Fewer studies have been done on the effectiveness of ACT interventions in lower resourced settings, but South African data is available. To address the pressure on inpatient bed availability, a modified ACT intervention was implemented in the Western Cape, South Africa in 2007, as part of a randomized controlled trial. Patients meeting a pre-defined high frequency user (HFU) criteria were randomly assigned to either the modified ACT intervention, or standard care. The intervention differed from standard ACT treatments by allowing for bigger caseloads and less frequent visits. After hour services were available via the standard on-call service.¹⁴ At one year follow-up it was demonstrated that focussing on maintaining adherence to treatment and offering additional support did not only reduce inpatient days but also improved psychopathology in patients with severe mental illness.¹⁵ A longitudinal study including the same study participants after three years of treatment found that assertive interventions can be successfully modified in under-resourced settings and sustain reductions

in in-patient usage over time, while remaining affordable and feasible within the context of a developing country.¹⁶

To date, there are no long-term studies focussing on ACT outcomes in lower resourced settings and for this descriptive study we aim to describe the clinical and demographic outcomes of the HFUs included in the initial ACT study 10 years after inclusion.

Methods

Study design

We conducted a retrospective review of the group of HFUs included in the first South African ACT trial, 10 years after inclusion.^{15,16} Patient data from both the intervention and control groups were reviewed.

Study setting

The study was conducted at Stikland Psychiatric Hospital in Cape Town, South Africa. The hospital provides in- and outpatient services to an area housing a population of approximately 1.7 million people.

The ACT team at the hospital consists of a part-time medical officer, social worker and psychiatrist as well as three full-time chief psychiatric nurses. The team has access to psychology, occupational therapy, a dual-diagnosis service, step-up step-down facility and PSR-based (psychosocial rehabilitation program) day program on a referral basis. The modified ACT team at Stikland Hospital differs from the international model by having bigger caseloads and less frequent home visits.

It is important to note that after the initial 12 month-study period, some control patients were included in the ACT intervention in order to give more patients the opportunity to benefit from the intervention. The team utilized a well-defined referral and discharge criteria, resulting in some patients being discharged from the ACT intervention during the course of the 10 years. Common reasons for discharge included 1) Clinical stability and engagement with community-based standard care services 2) Ongoing poor engagement with team/refusing home visits 3) Patients relocating. Discharge of stable patients/patients not engaging, allowed for the service to be available to more patients. However, if previously stable ACT patients relapsed after discharge from the service, they were automatically included again in the intervention.

Study sample

This study describes the same group of patients that were part of the first ACT study in South Africa.^{15,16} These were all high-frequency psychiatric users diagnosed with schizophrenia or schizoaffective disorder enrolled between January 2007 and March 2010. A total of 55 patients were retrospectively reviewed for their outcomes over 10-years. For a full description of inclusion criteria see Botha et al., 2010.¹⁵

Data collection

Data were obtained from patient folders and from the Clinicom Application Manager (a Western Cape hospital database keeping record on patient demographics, out-patient appointments and hospital admissions). Where no recent folders were available (16 patients that followed-up at community clinics only and one relocated out of the province) patients were contacted telephonically. All data were collated on a Microsoft Excel spreadsheet. Information was extracted for demographics, number of acute psychiatric hospital admissions, the total days spent in hospital over the 10-year period, admissions to other psychiatric services, adverse events as well as days spent in the ACT intervention.

Data analysis

For descriptive analyses, nominal data were summarised as counts and frequencies, while numerical data were summarised as means with standard deviation. All analyses were performed using SPSS version 26.0.

Ethical considerations

Ethical approval for the parent study was obtained from the Health Research Ethics Committee of Stellenbosch University (ref #: N06/07/140). An amendment was approved for this study, requesting a waiver of informed consent based on the retrospective nature of the study. All data were anonymised to ensure privacy and confidentiality of participants' personal information, with each participant assigned a unique identifier.

Results

A total of 55 patients were reviewed retrospectively, with no patients lost to follow-up. Initially, 30 patients (55%) were included in ACT while 25 (45%) received standard outpatient care. Of those initially included in ACT, nine (30%) patients remained in ACT for the full 10 years, two (7%) died while receiving ACT and one (3,3%) relocated to another province and subsequently died. The other 18 (60%) were discharged from ACT, two (5.5%) died subsequently and another three (16,6%) were later included again.

Of the 30 patients originally included in ACT, nine (30%) had no psychiatric readmissions. During the 10-year follow-up, 16 (53%) patients who received ACT had one or more

admissions to a step-up/step-down facility, two (7%) had forensic evaluations and none had admissions to long-term wards.

Of the 25 participants originally included in standard care, nine (36%) were included in ACT during the following 10 years, of which three (12%) were discharged later. Sixteen (64%) participants remained in standard care for the full 10 years, of whom three (12%) were never admitted again, two (8%) participants were admitted to long-term wards, and one (4%) died. For those who received standard care, five (20%) had one or more admissions to a step-up/step-down facility and two (8%) had forensic evaluations.

Study participants were predominantly male (76%) and had a mean age of 43 years (Table 1). Most participants lived in urban areas (91%), were single (82%) and spoke Afrikaans as their home language (91%). The overall group had a low level of education with only 12.7% having completed grade 12.

Table 1: Demographic variables for all study participants (n=55).

Age (mean \pm SD ^a)	43 \pm 9.69			
Sex	Female = 13 (24%)	Male = 42 (76%)		
Area of residence	Urban = 50 (91%)	Rural = 5 (9%)		
Marriage Status	Married = 4 (7%)	Divorced = 6 (11%)	Single = 45 (82%)	
Language	English = 1 (2%)	Afrikaans = 50 (91%)	Xhosa = 4 (7%)	
Education	Gr 12 = 7 (12.7%)	Secondary Education excl. Gr.12 = 28 (50.9%)	Elementary Only = 18 (32.7%)	No Formal Education = 2 (3.7%)

^aStandard deviation

For the overall sample, during the 10-year period five participants died, one by suicide (age 31), two from cancer at age 39 and 51, and two from unknown causes (aged 51 and 54 respectively).

Clear variations with regards to admission to acute psychiatric services were noted (Table 2), with some participants having had no admissions while others spent a large number of days in hospital, up to 2523 days. The mean number of days included in ACT was 1 699, with some participants from the original standard care group, never included in the ACT service while some participants in the intervention group spent the full 10-year period in this service. We noted no relationship between the number of days receiving ACT and number of days admitted to hospital acute services (Figure 1). There were two outliers who were admitted to long-term wards during the 10-year period and therefore had extended hospitalization times (> 1 500 days).

Table 2: Number of days in ACT in relation to access to acute hospital services.

Dimension	Mean	Minimum	Maximum	Standard Dev
Days included in ACT	1 699	0	3 650	1513.182
Number of Admissions	3.73	0	18	3.997
Number of Admission Days	261.11	0	2 523	481.251

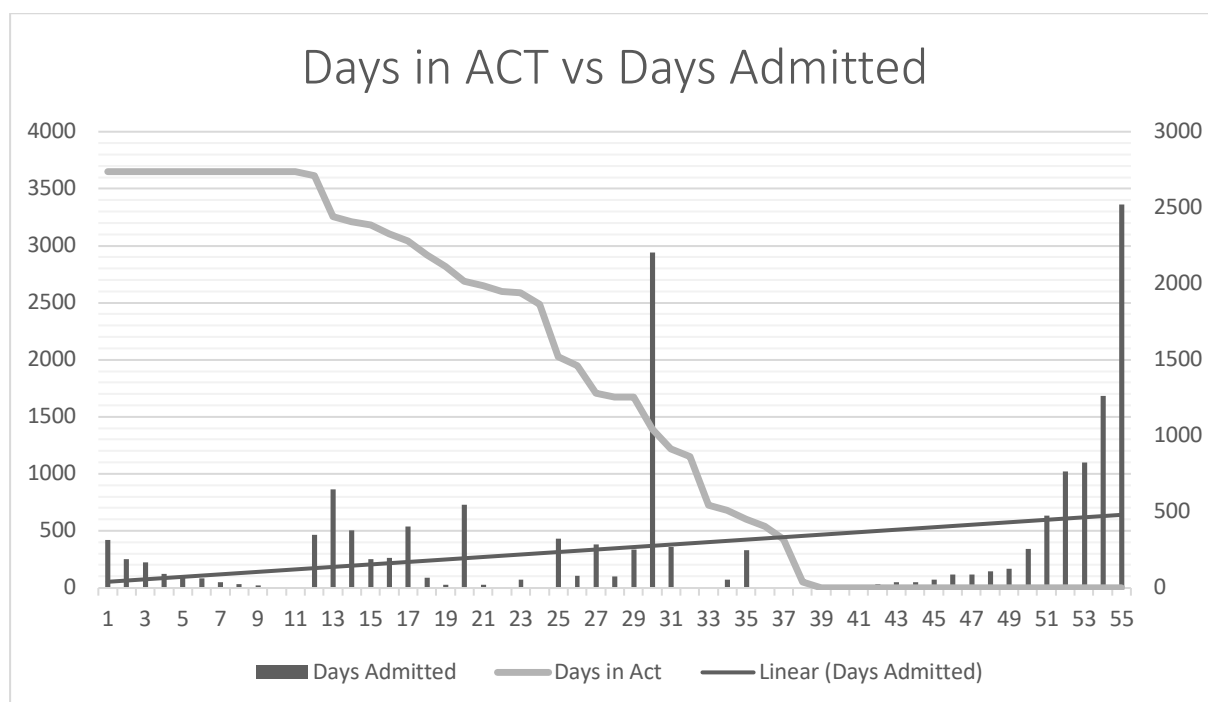


Figure 1: Comparison of the number of days included in ACT intervention with the total days admitted to hospital acute services.

Discussion

To our knowledge this is the only review reporting on 10-year outcomes of high-frequency psychiatric users in an under-resourced setting, to date. The study aimed to describe the outcomes of this group over a 10-year period. The small sample size and movement of patients between groups did not allow for a statistical comparison, but rather a description of the group in totality, with broad comparison for some outcomes. For example, for those who originally received ACT, we noted an increase in utilization of other available psychiatric services and a larger number having no readmissions during the 10-year follow-up period. This finding may suggest better overall engagement with psychiatric services for those receiving ACT. This is a consistent finding in studies reporting on ACT outcomes.¹⁷

Social outcomes from this 10-year longitudinal study correlated with results from the MRC ÆSOP-10 study, which reported poor social outcomes related to marriage, independent living and employment in their large sample of patients with schizophrenia when compared to the general population.¹⁸ The study concluded that social exclusion after a first psychotic presentation persists long-term.¹⁸ These expected social outcomes were more pronounced in our resource-poor setting, where only 12% had a high school education and more than 80% were reported to be single. The majority of the sample lived with family members, a common finding in studies reporting on this setting.¹⁶ Due to limited residential placement options, many patients are invariably discharged into the care of their family.

Schizophrenia has been associated with early mortality when compared with the general population.¹⁹ This early mortality has largely been linked to preventable causes that include trauma, suicide and cardiovascular complications.¹⁹ Furthermore, side-effects of antipsychotics include weight gain which could lead to diabetes, hypertension and dyslipidaemia, which are associated with cardiovascular complications.^{20,21} Patients with chronic mental illness often have a more sedentary lifestyle, which may further contribute to cardiovascular risks.

Sher et al. reported in 2019 that the lifetime suicide rate in patients with schizophrenia is 10%, with provision of comprehensive treatment reported to be the only reliable protective factor.²² Interestingly, the 10-year follow up of the ÆSOP first-episode cohort, reported comparatively high mortality rates, specifically those as result of unnatural causes, with the most common cause of unnatural deaths cited as suicide. Out of an overall sample of 549 participants, 13 (2.4%) had died as a result of suicide.²³ Considering all of the above, one might have expected a higher mortality rate in our group of high-frequency users. The patient who died as a result of suicide, had relocated and was discharged from the ACT service a year before her death. One possible explanation is that the support patients receive while in the ACT service, with frequent

contacts, review of medication and pro-active follow-up, may have reduced the impact of the factors that drive mortality in this group.

We noted a high utilization of step-up/step-down admissions for the group originally included in ACT (53% compared to 20%). Most admissions were “step-down” admissions from acute units, but some were “step-up” admissions as ACT outpatients. ACT key workers often facilitate step-up admissions for their clients to avert relapse or provide respite for families under pressure. This facility is a valuable resource and offers an 8-week PSR-based program under the guidance of a multi-disciplinary team.²⁴ The higher utilization of this service by ACT patients, supports the current evidence that ACT services promote engagement with services and facilitate use of other available resources.¹⁷

Duration of admissions varied, with some patients spending prolonged periods of time admitted to acute psychiatric services during the 10-year period. Two participants remained so unwell that they required extended admission to long-term wards. Long-term admissions are often utilized when patients have persistent symptoms that put them or their carers at risk, despite biological and psychosocial interventions.

There were however some patients who did not have any acute admissions during the 10-year period. The percentage of patients not requiring readmissions was larger in the group originally included in ACT (37% compared to 12% in the original standard care group). This may be the result of better adherence and symptom control, as a result of the pro-active approach of ACT staff in preventing relapse. These findings support the notion that the quality of outpatient services would be enhanced by incorporating some of the ACT principles. In a systematic

review performed in the UK in 2010, Burns et al commented that many so-called standard care community services had incorporated core ACT principles in their operating procedure, which resulted in comparatively similar outcomes to those delivered by ACT teams with small caseloads and frequent visits.⁶

An important consideration and possible limiting factor of this study is the small sample size and that a modified ACT strategy was employed. ACT keyworkers had significantly larger caseloads to oversee, with less-frequent contacts compared to the traditional ACT model. Another limiting factor was that some data, such as information about disability grants, was not available for patients who were followed up elsewhere. It would have been interesting to note if patients who spent time in ACT, were more likely to receive disability grants, as applications and re-applications would be facilitated by ACT key workers. After-hour services are also overseen by on-call doctors who may not know patients, and although the ACT team provided telephonic after-hour support to the doctor on-call, unnecessary admissions may have occurred. In addition to the above, the movement between groups during the 10-year period made direct comparison difficult. This was a patient-centred decision to give more patients the opportunity to benefit from the ACT intervention.

Conclusion

This study provided a unique perspective on the long-term outcomes of high-frequency psychiatric users who received a modified ACT intervention in an under-resourced setting. Although patients from both groups required readmissions during the 10-year period, a larger percentage of patients in the original ACT group had no readmissions in the follow-up period and their utilization of other resources (specifically the PSR-program) was higher than the standard care group. Future studies should include long-term follow-up of larger sample sizes

and consistent control groups to determine the effect of a modified ACT approach on admission rates and secondary outcomes, such as patient satisfaction, engagement with service and treatment adherence.

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Conflict of interest

The authors declare that they have no competing interests.

Author contributions

DC collected the data and wrote the manuscript. UB and LK conceived the study and supervised the project. DN performed data analysis. All authors provided critical feedback and contributed to the final version of the manuscript.

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