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Review Article

Frequency and Duration of Course of ECT Sessions: An Appraisal of Recent Evidence

Jagadisha Thirthalli, Shalini S. Naik, Girish Kunigiri[1]

ABSTRACT

Aims and Method: This paper aims to review the recent literature regarding factors influencing the frequency and number of sessions during a course of electroconvulsive therapy (ECT) for different psychiatric disorders. We systematically reviewed English-language papers of clinical trials of ECT published since the year 2000 in terms of frequency and number of sessions of ECT. **Results:** None of the 30 studies meeting our inclusion criteria were specifically designed to study frequency or number of sessions of ECT. A preliminary inference may be drawn regarding the number of sessions from the information available in these papers. For depression, patients receiving brief-pulse ECT needed fewer sessions than those receiving ultra-brief ECT when these were delivered at 8-times the threshold with unilateral electrode placement or at 2.5-times the threshold with bilateral placement. For schizophrenia, those receiving bifrontal ECT and ECT at 4-times the threshold-level stimulus needed fewer sessions than those receiving bitemporal ECT and 2-times the threshold-level stimulus, respectively. There were no clinical trials of the frequency of ECT sessions. **Clinical Implications:** As there is a dearth of studies specifically examining frequency and number of ECT sessions, broad recommendations from professional bodies should continue to guide practice.

Key words: Electroconvulsive therapy, frequency, schedule

Electroconvulsive therapy (ECT) continues to be an important treatment modality in psychiatry even after about eight decades of its first use. For well-defined indications, ECT is highly effective. An important concern regarding ECT is the cognitive adverse effects associated with it. A substantial body of research has concentrated on reducing the cognitive adverse effects while not compromising on its therapeutic usefulness. Researchers have explored variations in electrical aspects of the stimulus, electrode placement (EP), co-prescribed medications, anesthetic agents, etc., to achieve this. Frequency and number of sessions during a course of ECT are also important considerations in this context.

In this paper, we review the literature related to

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frequency and number of sessions during a course of ECT. Three influential sources reviewed the knowledge about these aspects in the early 2000s.[1-3] We first provide the gist from these sources; then, we follow this up with a systematic review of the research published since the turn of this millennium.

The frequency of ECT sessions has varied across regions and settings. In the US and Israel, thrice-weekly ECT is a common practice,[4,5] while in the UK, twice-weekly sessions are commonplace.[6] Some authors[7] have argued for 4-5 sessions of ECT per week to enhance the speed of recovery. Based on the extended research in this field, the Taskforce Report of the American Psychiatric Association (APA) on ECT[1] recommends twice or thrice weekly ECT sessions, with a caution that more frequent sessions could result in higher cognitive deficits and a suggestion that frequency of sessions should be reduced if cognitive effects are of serious concern. The Royal College of Psychiatrists' (RCP) ECT Handbook[2] recommends the use of twice weekly ECTs for bilateral ECT; it suggests that the use of thrice-weekly bilateral ECT should be reserved only for life-threatening illnesses and for as long as the threat is high. It suggests that unilateral ECT be administered twice weekly. In his book on ECT, Abrams[3] recommended the use of twice weekly ECT with bilateral ECTs; he also observed that biweekly ECT might need fewer sessions to achieve comparable efficacy as thrice weekly ECT.

The number of sessions in a course of ECT is largely determined by individual patient's response. Generally, the ECT course is stopped as soon as remission from symptoms is achieved or if the initial improvement remains unchanged for two additional sessions.[1] Research examining the optimum number of ECTs for different indications is sparse. APA task force report suggests 6–12 sessions for depression, with a caveat that given patients may need more or less than these number of sessions. The number could be higher for patients in whom ECT protocol was changed and those with schizophrenia. Based on the observation by Segman *et al*.,[8] the RCP handbook suggested that bilateral ECTs for depression may be stopped if there is no improvement at all during the first six treatments; if there is some improvement, then a substantial minority of patients would respond and, hence, it may be worthwhile continuing ECTs for up to 12 sessions. Abrams'[3] recommendations regarding bilateral ECT for depression were largely similar to the ones by the RCP handbook.

We aimed to review the recent literature about the number and frequency of ECT sessions. We examined the literature for factors that may influence the number and frequency of ECT sessions for different psychiatric conditions and synthesized the findings. These factors include anesthetic agents used during ECT, electrical aspects of ECT, and ECT EPs.

METHOD

For this review, we followed the relevant sections of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. We searched the PubMed database with the following search term: Electroconvulsive therapy [mesh]. We used "English," "clinical trials," "human," "articles with abstracts," and "publication dates between January 1st, 2000 and March 31st, 2019" as filters. A single author, SSN reviewed all the abstracts and selected papers that met the following inclusion criteria: the paper describes a clinical trial or posthoc analysis of data from clinical trials, and there is mention of the number of ECT sessions in the comparative groups or there is a comparison of different treatment schedules in terms of the number of ECT sessions. We excluded studies for reasons listed in Figure 1. SSN reviewed the full texts of all the selected studies and excluded further studies if they had both fixed number of ECT treatment sessions and fixed frequency of ECT treatments, no information was provided on both treatment schedules and total number of ECT treatment sessions, and if they were anecdotal case series/reports, articles on the same study cohort and reported the same observations,[9,10] or a study that was included in our previous review.[11] Figure 1 provides the details of this process. This systematic review protocol was not registered in any online database.

Each full-text paper was reviewed thoroughly, and the following details were extracted: aim of the study, sampling details, sample size, diagnosis, indication for ECT, comparison groups, details of anesthetic agents, details of electrical stimulus, EP, frequency of sessions, the total number of ECTs, and the reasons for terminating ECTs. In this paper, we focus on the findings on the frequency and number of ECT sessions. In some studies, there were major changes in ECT protocols (e.g. switching from unilateral to bilateral ECT). In such cases, we took into consideration only the details of the ECT sessions before the change.

We assessed the methodological quality of the studies using the Jadad score[12] if they were clinical trials. It is a system of evaluating the quality of clinical trials on the basis of randomization, blinding, and method of addressing dropouts. The score ranges from zero to five, a higher score indicating better quality.

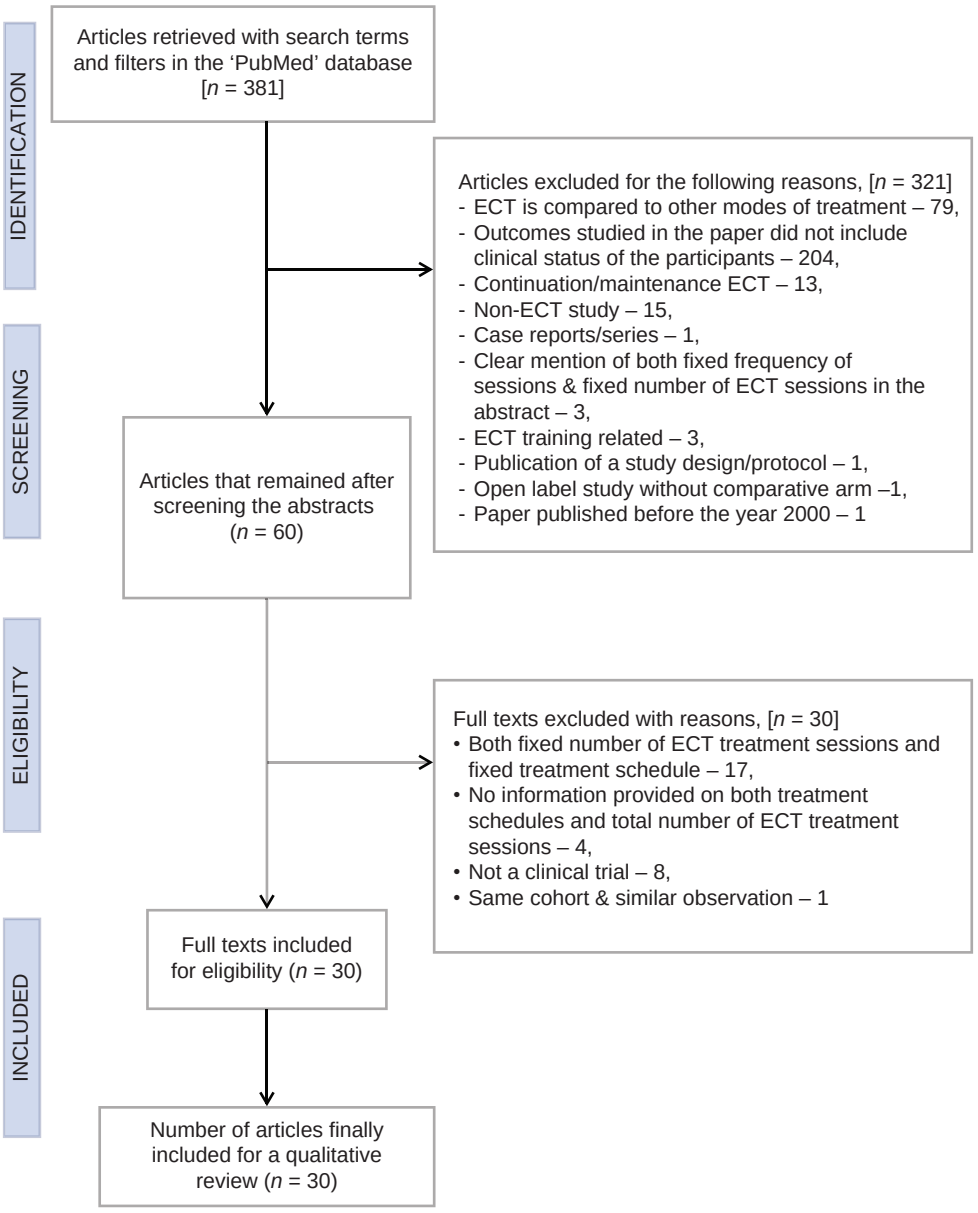

Figure 1: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart for the selection of studies

RESULTS OF THE SYSTEMATIC REVIEW

Table 1 shows the details of the studies reviewed. We classified the studies as those examining the effects of anesthetic agents, EP, stimulus parameters such as pulse width and stimulus intensity, concurrent use of anticonvulsants, and clinical characteristics. We have synthesized the results for each of these influencing factors.

To understand the importance of the number of sessions, it is vital to know the reason for the termination of ECT. In 8 (26.7%) of the 30 studies, there was no mention of the policy to determine the number of sessions. In all but one[13] of the rest of the studies, the decision was left to the treating clinicians. Nine (30%) of the 30 studies provided the details of patients in whom ECT was terminated because of adverse effects;[13-21] in all these studies, these numbers were too small for meaningful statistical analysis. However, none of the studies provided information about the proportion of patients in whom ECT was terminated due to a lack of clinical improvement.

Seven studies[14-16,22-25] examined the influence of anesthetic agents. All but two studies included patients with depression. Canbek *et al*.[24] included patients with diagnoses of mania, psychosis, catatonia, or depression. Tripathi *et al*.[23] included patients with depression, schizophrenia, or mania. In none of these studies, there was a significant difference between the compared groups in terms of the number of ECTs received [Table 1].

Table 1: Details of clinical trials included in the systematic review

First author, year [Type of clinical trial]	Aim of the study	Diagnosis [Treatment resistance status]	Sample	Reason for termination of ECT	Whether groups were compared for reasons for termination	Results for number of ECT in the groups Mean (SD)	Conclusion of the study regarding clinical outcome (other than number of sessions)	Change in treatment strategy	Blinding (Jadad score)[12]
Studies comparing anesthetic agents									
Ingram, 2007[22] [CT]	To compare efficacy and cognitive effects of 2 anesthetic agents during ECT	Depression [NM]	Thiopentone=12; Propofol=18	LC	No	Thiopentone=8.8 (3.2); Propofol=9.5 (3.5) *P*-n.s	Both were comparable	Switched from BL to RUL in 1 case in each group due to cognitive adverse effects	Rater-blinded (2)
Bauer, 2009[14] [CT]	To compare effects of 2 anesthetic agents on seizure duration, Stimulus charge, clinical effect, and cognitive side effects.	Depression [NM]	Thiopentone=31; Propofol=31	LC	Yes	Thiopentone=13 (NM); Propofol=10.2 (NM) *P*-n.s	Propofol[109.8 (49.5) mC] needed significantly (P=0.026) higher stimulus electrical charge [79.5 (50.7) mC] than thiopentone and both were comparable for clinical efficacy and cognitive profile	2 subjects of thiopentone group switched to RUL electrode placement due to post ECT confusion	Only rater blind (4)
Tripathi, 2014[23] [CT]	To explore effects of pre-treatment low dose propofol on the acceptance of ECT	Multiple diagnoses [NM]	Propofol - 49; Unmodified ECT -50	NA	No	Propofol-6.1 (2.1); Unmodified - 5.5 (2) *P*-n.s	Using low dose propofol pre-treatment did not compromise ECT efficacy and had reduced anxiety surrounding the treatment	No	None blinded (1)
Canbek, 2015[24] [CT]	To compare the effects of 3 anesthetic agents on cardiovascular system, seizure, recovery, cognitive functions, and response to treatment	Multiple diagnoses [NM]	Propofol=20; Etomidate=16; Thiopentone=15	LC	No	Propofol=8.4 (1.6); Etomidate=8.6 (2.5); Thiopentone=8.1 (1.7) *P*-n.s	Similar clinical improvement and CVS findings were observed without deterioration in cognitive functions in all three groups	No	Patients and rater-blind (3)
Loo, 2012[25] [CT]	To test neuroprotective and enhanced clinical efficacy effects of sub-anesthetic dose of ketamine as an adjunct anesthetic agent	Depression [Mixed]	Ketamine=22; Placebo=24	LC	No	Ketamine=9.5 (4.7); Placebo=9.7 (3.3) *P*-n.s	Sub-anesthetic dose of ketamine, given as an adjunct anesthetic agent did not show any additional benefit for clinical efficacy as well as cognitive side effects	Similar proportion of subjects received shift from RUL to BL in case of insufficient clinical response	Patients and rater-blind (5)
Fernie, 2017[15] [CT]	To establish if ketamine speeds up response to ECT with less cognitive impairment	Depression [NM]	Ketamine=20; Propofol=20	LC	Yes	Ketamine=7.9 (3.2); Propofol=7.3 (2.2) *P*-n.s	No significant difference ratings of depression severity or cognitive function	No	Patients, rater and treating psychiatrist-blind (5)
Carspecken, 2018[16] [CT]	To compare efficacy of 2 anesthetic agents	Depression [TR]	Ketamine=27; Methohexital=23	LC	Yes	Ketamine=5.5 (2.7) Methohexital=5.8 (1.6) *P*-n.s	Both are equally efficacious	Switching over to BL electrode placement to attain or enhance clinical response. [Ketamine - 1 (4%) Methohexital - 7 (26%) X2-4.41; *P*=0.03]	Patients and rater-blind (5)

Contd...

Table 1: Contd...

First author, year [Type of clinical trial]	Aim of the study	Diagnosis [Treatment resistance status]	Sample	Reason for termination of ECT	Whether groups were compared for reasons for termination	Results for number of ECT in the groups Mean (SD)	Conclusion of the study regarding clinical outcome (other than number of sessions)	Change in treatment strategy	Blinding (Jadad score)[12]
Studies comparing electrode placement (EP)									
Bailine, 2000[26] [CT]	To compare clinical and cognitive effects of two bilateral EPs	Depression [NM]	BF=24; BT=24	NA	No	BF=5.9 (2.5); BT=5.4 (2.5) *P*-n.s	Both EPs were comparable in efficacy	No	Rater blind (2)
Stoppe, 2006[13] [CT]	To compare efficacy and tolerability of 2 EPs given at fixed high dose	Depression [Mixed]	BL=22; RUL=17	By blind rater (PI) based on clinical response scored on MADRS	Yes	RUL -10 (3.5); BL-10 (2.8) *P*-n.s	Efficacy and speed of response were comparable;	No	Patient and Rater blind (3) ECT course decision maker was blind to EP
Hiremani, 2008[27] [CT]	To compare the short-term efficacy and adverse effects of two kinds of bilateral EP	Acute Mania [Mixed]	BF=17; BT=19	LC	No	BF=7.6 (2.9); BT=7.5 (2.7) *P*-n.s	Comparable clinical efficacy but BF had shown faster response than BT [Breslow statistic (1) = 5.52 (1); *P*=0.019]	No	Patient, Rater and Consulting clinician - blind (5)
Sienaert, 2009[10] [CT]	To compare the efficacy of 2 EPs using an ultrabrief pulse width	Depression [NM]	RUL=32; BF=32	LC	No	RUL=10 (3.6); BF=12.4 (5.9) *P*-n.s	Estimated odds of 2.7 times faster response with RUL at 6 times threshold-level stimulus in compared to BF at 1.5 times threshold-level stimulus at each evaluation (*P*=0.04; 95% CI: 1.065-6.893)	In 4 patients electrode placement (BF: *n*=2; UL: *n*=2) was changed to bitemporal or left UL because of poor response/adverse effects	Rater-blind (3)
Kellner, 2010[17] [CT]	To compare the efficacy and cognitive effects of BF with BT and RUL ECT	Depression [Mixed]	RUL=77; BF=81; BT=72	NA	Yes	RUL=5.9 (2.3); BF=6.2 (2.6); BT=5.5 (2.3) *P*-n.s	Efficacy was comparable across the three EPs.	No	Patient, rater-blind (5)
Phutane, 2013[28] [CT]	To compare clinical and cognitive effects of 2 BL EPs	Schizophrenia [Mixed]	BF=62; BT=60	LC	No	BF=7.5 (2.1); BT=8.4 (2.5) *P*=0.04	BF is advantageous over BT for short-term symptomatic and cognitive outcomes	No	Patient, Rater and Consulting clinician - blind (5)
Bjølseth, 2015[29] [CT]	To compare efficacy and safety of 2 EPs in elderly depression	Depression [Mixed]	BL=36; RUL=37	LC	No	BF - 7.7 (2.8); RUL - 8.4 (2.3) *P*-n.s	Efficacy and speed of response were comparable	No	Rater and patient-blind (5)
Dybedal, 2016[30] [CT]	To compare cognitive effects of 2 EPs in elderly depression	Depression [NM]	BL=31; RUL=34	LC	No	BF - 9.3 (3.6); RUL - 9.3 (3.0) *P*-n.s	Efficacy and cognitive effects were comparable	No	Rater and patient-blind (5)

Contd...

Table 1: Contd...

First author, year [Type of clinical trial]	Aim of the study	Diagnosis [Treatment resistance status]	Sample	Reason for termination of ECT	Whether groups were compared for reasons for termination	Results for number of ECT in the groups Mean (SD)	Conclusion of the study regarding clinical outcome (other than number of sessions)	Change in treatment strategy	Blinding (Jadad score)[12]
Semkovska, 2016[18] [CT]	To assess the effectiveness and cognitive side effects of moderate-dose bitemporal ECT with high-dose unilateral ECT in real-world practice	Depression [Mixed]	BT=69; RUL=69	LC	Yes	BT - 8.3 (2.4); RUL - 7.8 (2.5) *P*-n.s	Efficacy was comparable	No	Rater and patient-blind (5)
Studies comparing pulse width									
Spaans, 2013[19] [CT]	To examine antidepressive efficacy of UBP Vs BP RUL ECT, both at 8X ST	Depression [Mixed]	BP=38; UBP=50	LC	Yes	BP=7.1 (2.6); UBP=9.2 (2.3) *P*=0.001	Efficacy and speed of response of RUL is superior with BP compared to UBP with equal cognitive side effects	Switched to BL EP[UBP - 4; BP - 3] or thrice weekly treatment schedule[UBP - 1; BP - 0]	Rater and patient-blind (5)
Loo, 2015[31] [CT]	To examine clinical and cognitive outcome of 8ST UBP Vs 5ST BP RUL ECT	Depression [Mixed]	UBP=47; BP=48	LC	No	UBP=8.6 (3.4); BP=8.4 (3.2) *P*-n.s	Efficacy and cognitive profile were comparable	No	Patient, Rater and Consulting clinician - blind (5)
Studies comparing combination of electrode placement and pulse width									
Sackeim, 2008[32] [CT]	To explore effects of pulse width and electrode placement on the efficacy and safety of ECT [UBP-RUL Vs UBP-BL Vs BP-RUL Vs BP-BL]	Depression [Mixed]	UBP-RUL=22; UBP-BL=23; BP-RUL=22; BP-BL=23	LC	No	UBP-RUL=8.7 (2.4); UBP-BL=8.9 (2.5); BP-RUL=8.5 (2.5); BP-BL=6.2 (2.4) *P*<0.0001	Anti-depressant response of ECT in the UB-BL group was significantly poorer than in the other three groups (all *P*'s<0.001)	Nonresponders (no response after 10 ECTs) received an open, crossover course of brief pulse (1.5 ms) BL ECT	Rater and patient-blind (5)
Studies comparing stimulus intensity									
Chanpattana, 2000[33] [CT]	To examine the effects of electrical stimulus intensity on the speed of response and efficacy of BL ECT	Schizophrenia [TR]	ST=21; 2X ST=21; 4X ST=20	LC	No	ST=18.6 (5); 2X ST=12.5 (3.8); 4X ST=9.2 (1.5) *P*<0.0001	Responders and Remitters were the same across all three groups but faster response in high dose BL groups [*P*<0.0001]	Similar proportions of patients received 3 weeks of stabilization treatment schedule after attaining BPRS <25	Patient, rater, and consulting psychiatrist-blind (4)
McCall, 2000[34] [CT]	To compare antidepressant and cognitive effects of two dosing strategies of RUL ECT	Depression [NM]	Titrated moderate dose (2.5X ST) = 36; Fixed high dose of 403mC=36	LC	No	Titrated moderate dose (2.5X ST) = 5.7 (1.6); Fixed high dose of 403mC=5.6 (1.6) *P*-n.s	Both group were comparable however clinical efficacy and cognitive impairment showed dose-response relationship mathematically with stimulus dose relative to seizure threshold (SDRST)	If insufficient response, changed over to BL ECT ; No difference between the two groups	Patient, rater, and consulting psychiatrist-blind (5)

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First author, year [Type of clinical trial]	Aim of the study	Diagnosis [Treatment resistance status]	Sample	Reason for termination of ECT	Whether groups were compared for reasons for termination	Results for number of ECT in the groups Mean (SD)	Conclusion of the study regarding clinical outcome (other than number of sessions)	Change in treatment strategy	Blinding (Jadad score)[12]
Mohan, 2009[35] [CT]	To compare speed of improvement and remission rate with different stimulus intensities	Mania [Mixed]	ST=26; 2.5XST=24	LC	No	ST=7.6 (2.0); 2.5X ST=7.6 (4.4) *P*-n.s	Both were comparable	No	Patient, rater, and consulting psychiatrist-blind (5)
Studies comparing combination of electrode placement and stimulus intensity									
Sackeim, 2000[20] [CT]	To compare efficacy of various electrical stimulus dose strengths of RUL with standard dose of BT	Depression [Mixed]	1.5X ST RUL=20; 2.5X ST RUL=20; 6XST RUL=20; 2.5XST BT ECT=19	LC	Yes	6X ST RUL=8.3 (2); 2.5X ST RUL=9.2 (1.8) 1.5X ST RUL=9.9 (4); 2.5X ST BT=8.3 (2.2) *P*-n.s	High dose RUL and BL are equally efficacious and superior to low and moderate dose RUL	Non-responder (up to 10 ECTs) switched to standard EP [Data in each group-NM]	Patient, rater, and consulting psychiatrist-blind (5)
Heikman, 2002[21] [CT]	To compare efficacy of high and moderate -dose RUL ECT, and low dose BF ECT	Depression [TR]	5X ST RUL=8; 2.5ST RUL=7; T BF=7	LC	Yes	5X ST RUL=7(NM); 2.5X ST RUL=8(NM); T BF=12(NM) *P*-n.s	All three groups were comparable on clinical and cognitive parameters.	No	Patient, rater, and consulting psychiatrist-blind (5)
Tew, 2002[36] [CT]	To compare efficacy of 2.5X ST RUL ECT non responders after they were randomized to either 5.5X ST RUL or 2.5X ST BL	Depression [NM]	BF=11; RUL=13	LC	No	BF - 11.8 (2.8); RUL - 12.5 (1.7) *P*-n.s	BL ECT exhibited significantly greater cognitive impairment than RUL ECT by mean MMSE score difference of 2.8 (*P*=0.02) with equal clinical efficacy	No	Patient, rater, and consulting psychiatrist-blind (3)
Studies on concurrent use of anticonvulsants									
Jahangard, 2012[37] [CT]	To compare clinical outcome of concurrent use of Sodium Valproate during ECT course	Bipolar-Mania [NM]	On Valproate=21; Off Valproate=21	LC	No	On Valproate=7.71 (1.58) Off Valproate=7.04 (1.35) *P*-n.s	Continuation of Valproate neither adversely affected nor enhanced the efficacy of ECT	No	Patient, rater, and consulting psychiatrist-blind (5)
Rakesh, 2017[38] [CT]	To compare the impact of dose strengths of anticonvulsants on ECT	BPAD [Non-TR]	Full dose=19; half-dose=11; stop anticonvulsant=18	LC	No	Full dose=7.6 (2.3); Half dose=7.5 (2.8); Stop=7.5 (3) *P*-n.s	All groups were comparable for electrical charge, dose, seizure duration, clinical efficacy and cognitive side effects	No	Patient, rater, and consulting psychiatrist (5)
Studies comparing clinical characteristics									
Remitters Vs non-remitters									
Rhebergen, 2015[39] [PHA]	To identify course trajectories and putative predictors of ECT	Depression [Mixed]	Remitters=60; Responders=36; Non-remitters=24	NA	No	Remitters=7.5 (2.5); Responders=17.0 (9.0); Non-remitters=20.7 (4.7) *P*<0.001	Age positively influenced response to treatment. Mean age was significantly higher in remitters than in responders) [*F* (df) =6.3 (1) *P*=0.01]	No	NA

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Table 1: Contd...

First author, year [Type of clinical trial]	Aim of the study	Diagnosis [Treatment resistance status]	Sample	Reason for termination of ECT	Whether groups were compared for reasons for termination	Results for number of ECT in the groups Mean (SD)	Conclusion of the study regarding clinical outcome (other than number of sessions)	Change in treatment strategy	Blinding (Jadad score)[12]
Spaans, 2016[40] [PHA]	To investigate characteristics of remitters with ultra-brief pulse RUL ECT	Depression [Mixed]	Early complete remitters (ECR) = 12; Late complete remitters (LCR) = 9 Non-remitters (NR) =27	NA	No	ECR=5.2 (1.3); LCR=11.0 (1.2); NR=11.6 (1.2) $P<0.001$	Older patients [F (df) = 6.1 (1) $P<0.0001$] with psychotic depression [X2(df) = 5.5 (1); $P=0.01$] predicted rapid remission with ECT	Switched to BL EP or thrice weekly treatment schedule	NA
Diagnosis									
Sienaert, 2009[41] [PHA]	To compare response and speed of response of patients with UP and BP depression treated with ultra-brief pulse ECT	Depression [TR]	Unipolar=51; Bipolar=13	NA	No	Bipolar=6.9±3.05; Unipolar=9.5±3.84 $P=0.03$	Remission rates are same in both groups but faster response noted in BP group [t (48)=2.05, $P=0.05$]	In 4 patients, EP was changed to BT due to poor response or cognitive effects [Data in each group-NM]	NA

BF- Bifrontal ECT; BT – Bitemporal ECT; BP – Brief pulse; CT – Clinical trial; LC – Left to treating clinicians' decisions; NM – Not mentioned; NA- Not applicable; n.s – Not significant; PHA – *Post-hoc* analysis of clinical trials; RUL – Right unilateral ECT; ST –Seizure Threshold; TR – treatment-resistant; UBP –Ultra-brief pulse

Nine studies[10,13,17,18,26-30] investigated the effects of EP. Six of these compared right unilateral (RUL) EP with another EP. The rest three compared different bilateral EP with one another. Seven studies included patients with depression; Hiremani *et al*.[27] and Phutane *et al*.[28] examined patients with mania and schizophrenia, respectively. Phutane *et al*.[28] found that schizophrenia patients treated with bifrontal ECTs received one less session than those treated with bitemporal ECTs. Other studies found no difference in the number of ECTs between the compared groups.

Two studies[19,31] compared ECT with brief (BP) and ultra-brief (UBP) pulse widths in patients with depression. Patients in the BP ECT group received significantly less number of ECTs [Mean (SD) = 7.1 (2.6)] than those in the UBP group [9.2 (2.3)] by two ECT treatment sessions when both BP and UBP ECTs were administered using unilateral EP and stimulus at eight times the initial seizure threshold (ST).[19] However, BP-ECTs at five times ST and UBP-ECTs using unilateral EP at eight times ST were comparable.[31] One study[32] researched the effects of both EP and pulse width in patients with medication-resistant depression. Those in the UBP bilateral EP group had a significantly higher number of ECTs [Mean (SD) = 8.9 (2.5)] as well as a larger proportion of non-responders to ECT when compared to the three groups, UBP-RUL [8.7 (2.4)], BP bilateral [6.2 (2.4)], and BP-RUL [8.5 (2.5)].

Three studies[33-35] examined the effects of electrical stimulus intensity. Chanpattana *et al*.,[33] Mc Call *et al*.,[34] and Mohan *et al*.[35] included patients with schizophrenia, depression, and mania, respectively. Chanpattana *et al*. study showed that patients of treatment-resistant schizophrenia receiving high stimulus dosage bilateral-ECT [2ST = 12.5 (3.8); 4ST = 9.2 (1.5)] needed significantly less number of ECTs than those receiving low stimulus dose bilateral ECT [ST = 18.6 (5)]. The rest two did not find a significant difference in the number of ECTs.

Three studies[20,21,36] compared the clinical efficacy of various dose strengths of electrical stimulus using RUL EP with that of standard BL in patients with depression. None of them found a significant difference among compared groups with respect to the number of ECT treatments.

Two studies[37,38] explored the effects of concurrent use of anticonvulsants. Both were conducted in patients with bipolar affective disorder. Neither found any significant influence of continuing anticonvulsants in terms of the number of ECT sessions.

Two studies[39,40] explored the putative predictors of early response to ECT in depression. Expectedly, those

with early-course remission needed significantly less number of ECTs than late or non-responders. Older age,[39,40] use of BP stimulus waveforms,[31] and the presence of psychotic symptoms[40] were associated with early course remission.

Sienaert *et al*.[41] studied the speed of response to ECT in pharmacotherapy resistant depressive patients, comparing the polarity of their mood disorder. Patients with bipolar depression needed significantly less number of ECTs than those with unipolar depression by about three ECT sessions.

In two-thirds of the studies, the mean number of ECTs was between 6 and 10. In 4 (14.3%) studies, it was less than six and in 7 (25%) studies, it was more than 10. Patients (treatment-resistant schizophrenia) in the study by Chanpattana *et al*.[33] had received a substantially higher number of ECTs than the patients in other studies, but this number includes sessions of both acute course as well as the "stabilization" phase. Those with early and late remission in the study by Spaans *et al*.[40] received less than six and more than 10 ECT sessions, respectively, on an average. In Rhebergen *et al*.[39] study, patients with non-remission received up to 20 ECTs.

Of the 30 studies, 27 were clinical trials, and three studies were posthoc analyses of clinical trials. The quality of most studies was good. Eighteen (66.7%) studies had Jadad score[12] of 5. Two (7.4%), 4 (14.8%), 2 (7.4%), and 1 (3.7%) had Jadad score of 4, 3, 2, and 1, respectively.

We did not find any original research study examining the effect of the frequency of ECT sessions, published during the review period. Gangadhar and Thirthalli published a narrative review of studies of the frequency of ECT sessions in 2010.[42] They observed that for acute management of depression with bilateral ECT, the antidepressant effect was comparable between twice-weekly and thrice-weekly schedules. While a tendency of those receiving thrice-weekly ECT experiencing faster improvement was noted, it was associated with more cognitive deficits as well. Overall, the twice-weekly schedule had the best balance between efficacy and cognitive outcomes. Samples of most studies did not reflect patients who would receive ECT in clinical practice—for instance, in several studies, patients were either off antidepressant medications for a few weeks or were treatment-naïve at the time of the trials. Regarding acute management of schizophrenia and mania as well as continuation/maintenance ECT for any indication, the authors noted a serious dearth of quality studies to guide practice.

DISCUSSION

In this systematic review, we did not find any original research study examining the issue of frequency of ECT sessions. We found 30 studies that examined the number of ECT sessions. However, in none of them, the primary aim was to examine the number of ECTs—it was one of the secondary objectives in all these studies.

Studies researched a wide array of questions: the influence of anesthetic agents, EP, stimulus parameters such as pulse width and stimulus intensity, concurrent use of anticonvulsants, and clinical characteristics. A few studies reported significant results: Patients with schizophrenia receiving ECT with bifrontal EP had about one ECT session less than those who received ECT with bitemporal EP.[28] Patients with depression receiving brief-pulse ECT needed about two sessions less than those receiving ultra-brief ECT when both were administered with unilateral EP using stimulus at eight times the seizure-threshold.[19] When patients were treated for depression with bilateral ECT, those receiving brief pulse ECT needed about two sessions less than those treated with ultra-brief pulse ECT.[32] Treatment-resistant schizophrenia patients receiving bilateral ECT at four times their seizure-threshold needed seven and nine ECT sessions less than those receiving two times and barely above their threshold levels, respectively.[33] In depression, rapidly remitting patients received 10 and 13 ECTs less than slowly remitting and non-remitting patients, respectively.[39,40] Patients with bipolar depression received three ECT sessions less than those with unipolar depression.[41] In all these studies, as expected, the results for the number of ECTs reflected the findings on the efficacy of ECT measured using alternative methods. Most studies did not find a significant difference between the compared groups in terms of the number of ECT sessions. Interestingly, in three studies,[10,27,34] though there was a significant difference between comparison arms in terms of clinical outcomes, it did not reflect in the number of ECT sessions.

In all but one of the studies, the policy of when the ECT course is terminated was either not mentioned or was left to the clinicians. Clinicians may decide to terminate ECT sessions based on several factors: achievement of therapeutic target (i.e., some threshold of improvement), plateauing of response after an initial improvement, development of significant adverse effects (particularly cognitive ones), or as per the patients' choice. Unfortunately, the proportion of patients in whom the ECT course was terminated for different reasons is not mentioned in these papers. Hence, the interpretation of both the positive and the negative findings becomes hard. In most studies, the

mean number of ECT sessions was between 6 and 10; in the absence of data on reasons for stopping ECT between responders and non-responders, it is difficult to interpret this finding as well.

It is apparent that when rapid improvement is clinically warranted, thrice-weekly ECT may be preferred. Given that both twice-weekly and thrice-weekly ECTs are equally efficacious, what are the cost implications when clinical situations do not warrant rapid improvement? Costs depend on the number of ECT sessions and duration of inpatient stay. In the UK, for instance, six treatment sessions of ECT cost about £ 2475;[43] inpatient costs are estimated as about £ 171 per day. Unfortunately, the current literature does not provide useful insights into this important aspect. Of the four studies that compared twice- vs. thrice-weekly ECTs in depression, three used bilateral ECT, which is recommended to be used only when there is clinical urgency. The only study that used unilateral ECT[44] did not specify the dose of the electrical stimulus, and hence, it is uncertain if it reflects contemporary ECT practice. Among the ones which studied bilateral ECT, one study[45] had fixed the number of ECTs, and hence it is not possible to assess the cost advantage; two other studies[5,46] found that patients receiving thrice-weekly ECT received more sessions than those receiving twice-weekly ECT. However, the criteria used for termination of ECT in these studies do not reflect clinical practice, and hence, the translational value of this observation is doubtful.

ECT is frequently used in situations where rapid improvement is required, e.g. acutely suicidal/catatonic/aggressive patients. In fact, APA taskforce observes, "primary use of ECT should be considered when a rapid or a higher probability of response is needed, such as when patients are severely medically ill or at risk to harm themselves or others." ECT is also frequently used when medical conditions (including pregnancy) either preclude the use of a full dose of antidepressants or warrant urgent relief of symptoms. There are two important reasons as to why literature from clinical trials may not be useful while making clinical decisions: (a) Most ECT literature comes from research conducted on patients who do not belong to the above categories. (b) When clinicians use ECT for such indications, then the number of ECTs and the decision to terminate a course may depend on a number of factors including achieving a specific clinical target (for example, reduction of suicidal risk, resolution of catatonic symptoms, patient starting to eat, etc.) and not necessarily because the patient had achieved response, remission, or plateauing of response.

Barring a few studies,[24,34,37,40] the SD for the number of sessions is more than 2. It is reasonable to assume that the difference in the mean number of ECT sessions between the compared groups should be at least one for the finding to be clinically meaningful. For studies to show a clinically meaningful difference of one session between the compared groups with a conservative estimate of SD of 2 (i.e., a standardized mean difference of 0.5), the sample size in each of the compared groups should be about 60 in each group with 80% power and with type-1 error rate of 0.05.[47] It may be noted that most studies included much smaller samples and hence were underpowered with regard to the number of ECT sessions.

As described in the introduction section, professional bodies[1,2] and authors of textbooks on ECT[3] have made certain recommendations regarding the frequency of ECT sessions in the early 2000s. This review of the past two decades of research adds little to these recommendations. Regarding the recommendations about the number of ECTs, this review suggests that those receiving ultra-brief pulse ECT for depression and those receiving threshold-level stimulus with bilateral ECT for schizophrenia would require a greater number of ECT sessions, albeit with the caveats discussed above.

CONCLUSIONS

Frequency and number of sessions are important clinical aspects of ECT practice. In this paper, we attempted an appraisal of research pertaining to these aspects. There is a serious dearth of contemporary literature specifically examining these questions. The information available from studies with different aims provides important insights, which need to be pursued in future research. Until then, the broad recommendations suggested by professional bodies[1,2,48] should continue to guide ECT practitioners.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Cross-Disciplinary Appraisal of Knowledge and Beliefs Regarding the Diagnosis of Autism Spectrum Disorders in India: A Cross-Sectional Survey

Atika Jain, Shivani Tiwari, Sebastian Padickaparambil[1]

ABSTRACT

Background: Many healthcare professionals, including pediatricians, psychiatrists, Clinical Psychologists (CPs), Occupational Therapists (OTs), and Speech-Language Pathologists (SLPs), are involved in the identification and intervention of Autism Spectrum Disorders (ASD) in children. Distinctive training backgrounds and professional exposure can result in contrasting ideas regarding the assessment, diagnosis, and treatment of ASD. Only a few studies have addressed the cross-disciplinary perspective of knowledge, belief, and awareness about diagnostic criteria required for diagnosing ASD. **Materials and Methods:** A total of 154 allied healthcare professionals (98 SLPs, 33 CPs, and 23 OTs) participated in the study. The survey tool used for this study was adapted from a previously available survey on the assessment of knowledge and belief about ASD and self-efficacy. **Results:** The overall knowledge and belief of allied healthcare professionals regarding ASD differed significantly across the groups. However, the knowledge of Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) diagnostic criteria for ASD did not differ significantly between the groups. **Conclusion:** Our findings have salient clinical implications and advocates for the continued education of healthcare professionals in India regarding recent diagnostic criteria for ASD.

Key words: *Allied healthcare professionals, autism, India*

Key Message: *While knowledge and belief of professionals regarding autism differed, the knowledge about ASD diagnostic features did not differ significantly between the groups (SLPs, OTs, and CPs). Continued education of healthcare professionals is needed regarding recent diagnostic criteria for ASD.*

Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders characterized by difficulty in social communication skills and the presence

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of restricted interests and repetitive behaviors.[1] ASD is indeed a spectrum of conditions, with considerable variability across individuals in cognitive function, language ability, and psychiatric and neurological comorbidities.

Kanner[2] stated that three primary characteristics are necessary to identify autism. They are difficulty in social interaction, qualitative impairments in communications, and restricted, repetitive, and stereotyped behavior, interests, and activities. One of the following characteristics should be observed before the age of 3 years. Children with autism show marked social difficulties like lack of awareness of feelings towards others, preferences for being alone, unable to comprehend social rules and conventions, a failure to take help from others during distress, difficulty to imitate the actions of others, and a lack of social and creative play. Nevertheless, symptoms of ASD, like repetitive and stereotypic behavior patterns and social deficits, might not be identified until a child is not able to meet educational, occupational, social, or other demands that are important for life. Limitations in functional abilities may vary among persons with ASD and might develop over time.[3]

Autism is often identified and diagnosed in various clinical settings. The diagnosis of autism is carried out by numerous healthcare professionals, including psychiatrists, pediatricians, medical practitioners, clinical psychologists (CPs) and school psychologists. Subsequently, children with ASD are seen by speech-language pathologists (SLPs) and occupational therapists (OTs) for speech, language delay, and developmental concerns. Since the identification and diagnosis of children with ASD are performed in numerous settings, the process of diagnosis and treatment is frequently not easy and smooth.[4] Hence, the procedure is usually lengthy and confounded by diagnostic confusion, which can increase the time taken for proper diagnosis and duration of management.[5] Furthermore, an obsolete and incorrect belief about prognosis and management of ASD can affect the counseling which the professionals are likely to provide the parents of children with ASD. Therefore, continued training in recent research is essential for accurate diagnosis and treatment of ASD. While various studies have been done to evaluate the nature and treatment of ASD, only limited studies have been conducted to examine the cross-disciplinary comparison of knowledge and belief about ASD that can affect the diagnostic decisions across the settings.

Thus, the present study aimed to investigate and compare the knowledge and belief of allied healthcare professionals (SLPs, OTs, and CPs) involved in the rehabilitation of children with ASD in India. The objectives of the study were to evaluate and compare the knowledge and belief of allied healthcare professionals on ASD and to evaluate and compare the knowledge of allied healthcare professionals regarding the diagnostic criteria for ASD.

METHOD

Study design

A time-bound cross-sectional research design was used. Purposive sampling was adopted for data collection.

Participants

All the participants in the study were qualified and practicing SLPs, OTs, and CPs in India. Professionals who had completed their undergraduate degree and were working and/or doing their graduation in the fields of SLP and OT and M Phil Clinical Psychology trainees were included. Professionals who had studied in India but are working abroad or vice-versa were excluded.

Assessments

The survey tool (questionnaire) used for this study was adapted (with permission for use in the Indian context) from the survey used by Ben-Sasson and Atun-Einy in their study on the assessment of knowledge and belief about ASD and self-efficacy.[6] The original questionnaire consists of three sections, wherein an additional section on demographic details was added for use in the present study. Section III of the original survey (on self-efficacy) was not included in the current study, as many participants were not comfortable with this section, particularly the self-competence questions. Finally, our questionnaire consisted of the following three sections:

Section I comprised of nine questions collecting the participant's background details such as name, age, gender, qualification (undergraduate, graduate, M. Phil, Doctorate), professional background (OTs, SLPs, or CPs), duration of clinical experience, the experience of handling cases with ASD, the total number of cases seen, and the nature of the workplace.

Section II consisted of 43 statements assessing knowledge and beliefs related to ASD. The rating scale used was a 6-point Likert scale and a column of "I don't have specific knowledge about the topic". Obtained responses on the 7-point rating scale were coded as follows: 1 was coded as *fully disagree*, 2 as *mostly disagree*, 3 as *somewhat disagree*, 4 as *somewhat agree*, 5 as *mostly agree,* and 6 as *fully agree*. The response "I don't have specific knowledge about this topic" was coded as 0.

Section III consisted of 26 items related to knowledge about autism features for diagnostic purposes based on

the DSM-5 criteria. Respondents were asked to rate each of the 26 features related to autism as "obligatory," "comorbid/helpful but not necessary," "not relevant" for the diagnosis. This section also included two open-ended questions on early signs and on who are at increased risk for ASD.

The final study protocol was approved by the Institutional Research Committee and the Institutional Ethics Committee.

Validation of the survey tool

Before the commencement of the study, the content validation of the questionnaire was carried out by an experienced professional from each of the three professional groups under study. They were asked to provide their agreement/disagreement against each statement/question for all sections of the questionnaire. Further, comments were elicited on how individual statements/questions might be modified for better understanding.

Procedure

In the preliminary stages, the contact details of the practicing professionals from each of the disciplines were collected from the institutional websites, their corresponding national association sites, and alumni sites. Information about the study was mailed to them, and informed consent was taken through email.

A web link, prepared using Google forms, was sent to all the participants who consented to participate, with detailed instructions about filling in the questionnaire. The survey link was open for participants for about 4 months. Reminders were sent at regular intervals (nine reminders in total were given at an interval of 15 days).

Scoring and analysis

All obtained responses were tabulated and numerically coded in an Excel datasheet. Responses obtained in Section I of the questionnaire (participants' background details) are presented using descriptive statistics (frequency and percentages). Responses for Section II (knowledge and belief between allied healthcare professionals), using a Likert scale, were numerically coded (as described above in the material section) and computed. One-way Analysis of Variance (ANOVA) was used to compare the responses across the groups. Section III responses (knowledge of DSM-5 diagnostic criteria for autism) were scored as one for each correct response and zero for an incorrect response. Further, one-way ANOVA was performed to compare the scores between the groups. The responses obtained from the two open-ended questions regarding the DSM-5 diagnostic criteria were analyzed by listing all answers and identifying common answers/themes with respective frequencies. The responses received in this section were then compared with the DSM-5 criteria for the correctness and are discussed accordingly.

RESULTS

The questionnaire was checked for content validation by professionals each in SLPs, OTs, and CPs team. All three professionals provided a 100% agreement for all the sections of the questionnaire, thereby making a 100% Kappa score. A test of Cronbach's alpha was performed to check for the internal consistency of the questionnaire. Cronbach's alpha for 43 knowledge and belief statements was found to be acceptable ($\alpha = 0.795$). However, Cronbach's alpha for 26 items in diagnostic features was found to be slightly low ($\alpha = 0.538$).

The web-based survey was sent out to 938 participants, and responses were obtained from 154, showing a response rate of nearly 17%. The 154 participants comprised of 98 SLPs (64%), 33 CPs (21%), and 23 OTs (15%). This included 133 (86%) females and 21 (14%) males. All the 154 participants had managed children with ASD; the majority have seen 30 + cases (37%; $n = 57$), followed by 11–20 cases (29%; $n = 44$), 1–10 cases (25%; $n = 38$), and 21–30 cases (8%; $n = 15$). Sixty-three (41%) participants had a clinical experience of 1–5 years, 49 (32%) more than 5 years, and 42 (27%) less than 1 year. Participants worked in a variety of clinical settings such as a combination of various settings (38%; $n = 58$), followed by institutional (32%; $n = 49$), hospital (18%; $n = 27$), private clinic (11%; $n = 17$), and school (2%; $n = 3$).

One-way ANOVA revealed a statistically significant difference between groups [F (2, 151) = 5.206, $P = 0.007$] on the comparison of total scores obtained on knowledge and belief among allied healthcare professionals (SLPs, CPs, and OTs). A Bonferroni post-hoc test revealed significant differences in knowledge and belief scores between the SLPs and OTs ($P = 0.028$), and between OTs and CPs ($P = 0.006$). However, there was no statistically significant difference between the knowledge and belief scores of SLPs and CPs ($P = 0.654$).

Further, the results of one-way ANOVA for comparison of total scores on the knowledge of DSM-5 diagnostic features of ASD across professionals did not reach a significance, F (2, 151) = 1.164, $P = 0.315$. Table 1 presents participants' total scores on knowledge, belief, and knowledge of the DSM-5 diagnostic features of ASD.

The responses obtained on the two open-ended questions, "What early signs in a baby under your care raise your concern for ASD?" and "In your opinion, which babies are at increased risk for ASD?" were tabulated and grouped and the respective frequencies were obtained for each of the participant groups. Participants' responses on the two open-ended questions are presented in Tables 2 and 3, respectively.

DISCUSSION

A multidisciplinary approach, including mental health professionals and allied healthcare professionals, is preferred for the treatment of developmental disorders like ASD.[7] Therefore, professionals need to update their knowledge in this field.

The results of the study revealed an overall significant difference regarding knowledge and beliefs but particularly not for the knowledge of diagnostic features regarding the assessment of ASD among allied healthcare professionals in India. Further, the analysis of knowledge of diagnostic criteria used for evaluation of ASD showed a range of responses, thereby indicating the extent of knowledge in the allied healthcare professionals working in India. These findings are discussed in the following sections.

Comparison of knowledge and belief related to ASD

The results for the comparison of knowledge and belief related to ASD showed that the overall knowledge of participants differed between professions. Differences were revealed in the comparisons of knowledge and belief of SLPs and OTs, and OTs and CPs but not between SLPs and CPs. Similarly, the SLPs and OTs were more likely to endorse the old view that the cause of ASD was a parental bonding, and child attachment difficulty. The etiological credit, once assigned to aloof, rejecting parenting has been now shown to be irrelevant by researchers in the field. Researchers, since the 1960s, have acknowledged that parental factors and pathogenesis are not causal in ASD.[8] When compared to CPs, the majority of SLPs and OTs believed that children with ASD find difficulty in making eye contact with others. Literature suggests that early interventions can help to improve deficits such as children's communication skills, attention, and social interaction skills, and hence early intervention is crucial.[9] Two of the professional groups (i.e., SLPs and OTs) in the study were likely to endorse that, ASD has a firm genetic basis, thereby supporting the views from research that the behaviors associated with autism are likely attributed to the etiological factors, such as underlying neural and genetic factors.[10] A large percentage of SLPs and OTs (in comparison to CPs), reported not knowing the suitability of the Developmental, Individual difference, Relationship-based (DIR) model[11] for children with high functioning autism. Many of the OTs, followed by SLPs and CPs, continue to hold the belief that, children with ASD can outgrow the disorder with proper treatment. The literature shows that the effects of treatment vary according to the severity of impairment,

Table 1: Comparison of participants' total scores on knowledge and belief section of the survey

	Allied healthcare professional group (s)	*n*	Mean (SD)	95% CI for mean	
				Lower Bound	Upper Bound
Knowledge and Belief total scores	SLP	98	157.20 (19.37)	153.32	161.09
	OT	23	168.26 (17.15)	160.84	175.68
	CP	33	152.70 (14.34)	147.61	157.78
Knowledge of DSM-5 criteria	SLP	98	14.90 (2.54)	14.39	15.41
	OT	23	15.83 (2.58)	14.71	16.95
	CP	33	15.24 (3.13)	14.13	16.35

SLP: Speech-Language Pathologist; OT: Occupational Therapist; CP: Clinical Psychologist; *n*: sample size; SD: Standard Deviation; CI: Confidence Interval

Table 2: Participants' response to the open-ended question "What early signs in a baby under your care raise your concern for autism?"

Response(s)	SLPs	OTs	CPs
Core features			
Social interaction deficits	102	31	41
Communication deficits	14	3	7
Stereotypic behaviors	20	2	14
Developmental features			
Sensory	5	6	1
Motor	10	5	3
Communication	49	6	11
Cognitive	20	4	2
Behavioral	13	4	4
Emotional	1		
Total	234	61	83

SLPs: Speech-Language Pathologists; OTs: Occupational Therapists; CPs: Clinical Psychologists

Table 3: Participants' response to the open-ended question "In your opinion which babies are at increased risk for autism?"

Response(s)	SLPs	OTs	CPs
Biological factors			
Genetic	43	5	20
Birth-related	30	7	20
Neurological	7	2	4
Parental	7	3	6
Environmental factors	54	26	6
Familial	4	3	1
Social	2	3	-
Others	3	1	-
Nil	9	1	1
Total	159	51	58

SLPs: Speech-Language Pathologists; OTs: Occupational Therapists; CPs: Clinical Psychologists

where the prognosis for children falling in the more profound/severe end of the spectrum, typically requiring a supervised living placement throughout adulthood. Children falling in mild end of the continuum are often able to achieve adequate functioning in language and social behavior but are still likely to retain some persistent speech and behavioral peculiarities.[12] In the present study, the differences exhibited by the allied healthcare professionals on knowledge of the treatment of ASD could be attributed to relatively less literature available in the Indian scenario, and a lack of understanding of the disorder.

When compared to SLPs, a large percentage of CPs, followed by OTs, continue to hold an outdated belief that most children with ASD are mentally disabled. At the same time, the allied healthcare professionals agreed that children with ASD are more intelligent than appropriate testing indicates, a finding consistent with the existing literature.[13] There is a significant shift in the understanding regarding the cognitive aspect and intellectual functioning of ASD. Initially, Kanner[2] believed that children with ASD have average intellectual potential. This view was derived from Kanner's observation of peak cognitive skills in his samples. Many studies have consistently reported that the majority (nearly 70%) of children with ASD function within the mentally retarded range.[14] The very first cross-disciplinary study by Stone[5] found ASD specialists' responses also supported this fact.[14]

SLPs and OTs were more likely to endorse a higher prevalence of ASD in the higher socioeconomic groups/educational levels. However, recent epidemiological research suggests that ASD occurs across socio-economic status.[6] This result mainly demonstrates the tendency to hold on to outdated beliefs as initially presented by Kanner.[2] Thus, the finding of this study is consistent with previous studies displaying differences and misperceptions about various aspects of ASD across disciplines.

Comparison of knowledge about diagnostic features of ASD

This section of the survey was more directly related to the diagnosis of children with ASD. Professionals from different fields employ different criteria for the determination of ASD, though more commonly the DSM criteria. A comparison of the total scores showed no significant difference in the knowledge of diagnostic criteria between allied healthcare professionals. However, their understanding of ASD features differed significantly for five out of a total of 26 behaviors (i.e., hallucinations, sudden unexplained mood changes, attention deficit, lack of coordination between verbal communication messages and nonverbal communication messages, and difficulty in social responsiveness). This difference could be attributed to the fact that new DSM-5 criteria are not practiced widely in India when compared to western countries. Furthermore, in the Indian context, CPs are mainly involved in the process of diagnosis of autism when compared to other allied professionals. This could have resulted in the CP's knowledge about DSM-5 criteria being better when compared to SLPs and OTs.

As per the DSM-5 diagnostic criteria, the deficit in nonverbal communicative behaviors used for social interaction (poor integrated – verbal and nonverbal communication, poor eye contact and body language, or deficiencies in understanding and use of nonverbal communication) are considered as the core features in the diagnosis of ASD. The results of the study were found to be consistent with the DSM-5 criteria, where, CPs showed better endorsement when compared to OTs and SLPs for item "Lack of coordination between verbal communication messages and nonverbal communication messages." As per diagnostic criteria used for autistic disorder, "hallucinations," "sudden, unexplained mood changes," and "thought disorders" are irrelevant features and as per the results from the present study, CPs showed better knowledge than SLPs and OTs. Furthermore, the only feature "lack of reasoning and solving everyday situations" (an assistive feature as per DSM-5 criteria), was the one where SLPs and OTs presented better knowledge compared to CPs.

Participants' responses on the open-ended questions in the DSM-5 diagnostic criteria for ASD, viz "What early signs in a baby under your care raise your concern for ASD?" revealed many signs as weak social interaction, poor eye contact, inadequate social smile, and so on. Another question, "In your opinion, which babies are at increased risk for ASD?" also showed many factors like inadequate parent-child interaction, preterm babies, genetic predisposition, and so on. The responses obtained from the professionals were mostly consistent with the literature on early signs and risk factors for ASD.[15,16] The responses obtained on the open-ended questions related to early signs and risk factors in the identification of children with ASD also show that the allied healthcare professionals were knowledgeable regarding the diagnostic features and causes.

The findings of the study showed a significant difference regarding the knowledge and beliefs of allied healthcare professionals, though the difference was not significant for knowledge of diagnostic features regarding the assessment of ASD. However, assessment of the participants' knowledge of diagnostic criteria used for evaluation of ASD revealed a range of responses, indicating that allied healthcare professionals are

increasingly aware of the identification of ASD. This could also be attributed to the present-day curriculum of these professionals, where ASD and interventions specific to their field are taught in detail.

One of the drawbacks of the study was that the sample size was uneven across the groups of professionals. It is possible that the results do not reliably reflect the perspectives of the professionals. Furthermore, a few of the participants from various professional groups were students doing their graduate and M Phil studies, which would have influenced the outcome of the study.

Future studies are thus recommended to validate the findings of the present study. The findings of the study have salient clinical implications and advocate for the continued education of healthcare professionals regarding recent diagnostic criteria for ASD in India. Besides, recognition of cross-disciplinary differences may be the step towards transcending these differences.

CONCLUSION

The present study investigated the cross-disciplinary comparison of knowledge and belief in the assessment of children with ASD for the first time in the Indian context. The results provide an essential overview of the knowledge, belief, and diagnostic practices of ASD from a developing country. The study offers support for the contention that perspectives on a single disorder can differ from one discipline to the next. Further, the knowledge about ASD diagnostic features did not differ significantly between the groups (SLPs, OTs, and CPs). While the findings of this study have clinical implications for the education and training of healthcare professionals in India, future studies are recommended to validate our findings.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Stress and Coping Styles in Mothers of Children with Autism Spectrum Disorder

Nivedhitha Selvakumar, Anuja S. Panicker[1]

ABSTRACT

Background: Children with autism spectrum disorder (ASD) require well-balanced care and a comprehensive therapeutic approach. Mental health problems often go unnoticed in mothers of children with ASD due to the focus on training for the children. The presence of stress and depressive symptoms in mothers can interfere with the quality of care and therapy given to the child. The present study aimed to assess the quality of life, coping styles, and symptoms of depression, anxiety, and stress in mothers of children with ASD. **Methods:** This study recruited thirty mothers of children with ASD, to whom Depression, Anxiety and Stress Scale (DASS 21), WHO Quality of Life Scale (WHOQOL-BREF), and COPE Inventory were administered. **Results:** Results indicated the presence of depressive and anxiety symptoms and impaired quality of life among the mothers. Despite this, they exhibited positive coping styles. **Conclusion:** As part of a comprehensive intervention for children with ASD, there is also a need to address the psychological distress and coping styles of mothers.

Key words: *Anxiety, autism spectrum disorder (ASD), coping styles, depression, quality of life, stress*

Key messages: *The mothers of children with ASD are vulnerable to develop symptoms of depression and anxiety. They are also more likely to have an impaired quality of life. Hence, it is of paramount importance to focus on their mental health needs, in order for the mothers to be able to efficiently deliver behavioral interventions to children with ASD.*

In India, it has been estimated that more than two million people might be affected by autism spectrum disorder (ASD),[1] with a pooled percentage prevalence of 0.11 (1–18 year age group) in the rural areas and 0.09 (0–15 year age group) in the urban areas.[2]

ASD involves persistent impairments in language, social skills, and daily life activities, which persist throughout the lifespan. Approximately two-thirds of children with ASD are unable to live independently, and only 1% can achieve any degree of personal autonomy as adults, which imply a high workload and ongoing concern for the caregiver.[3] These factors may affect the way the parents deal with the child and possibly create a rift in the relationship between the family members.

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The preponderance of deficits, variability in ASD severity and functioning, and the lifelong nature of the condition complicate service planning and necessitate prioritization to address the expressed needs and individualized care at different life stages.[4,5]

The caregiving process often requires additional physical, emotional, social, and financial resources.[6] Parents of children with neurodevelopmental disorders have the additional responsibility of giving focused inputs for overcoming the deficits in the child, along with the usual child-rearing practices. This often makes the parents experience excess pressure and a sense of inadequacy about their parenting skills. This can result in parental stress if the parents' perceptions of the demands of their parental role exceed their coping resources, without being able to restore an equilibrium through the usual methods and strategies.[7]

The stress experienced by parents of children with ASD, which reaches clinically significant levels in 77% of the cases,[8,9] has been found to be greater than the stress of parents with children with typical development.[10-14] The levels of parental stress also exceed the stress of parents with children with other neurodevelopmental disorders, such as specific learning disorders, intellectual disabilities, Down syndrome, cerebral palsy, externalizing behaviors, or attention deficit hyperactivity disorder.[15-18]

Parents play an important role in the overall development of a child with a disability. Rahman *et al*. (2016) have established the feasibility and acceptability of the parent-mediated intervention for ASD in India.[19] Mental health difficulties in parents can impair their involvement in such interventions. The severity of the core features of autism has been found to be related to parenting stress[20] and maternal psychopathology symptoms.[21] Specifically, self-isolated/ritualistic and repetitive behaviors are associated with poorer parent outcomes and the mothers' anxiety and depression.[22] The problems of children with ASD seem to affect different domains of parenting stress. Parental distress is predicted by behavioral and emotional problems in the children, whereas stress related to a dysfunctional parent-child relationship is associated with daily living, communication skills, and cognitive abilities.[23] Based on a review of 133 studies, behavioral problems of children with ASD, particularly externalizing problems, were found to be linked to parental stress.[24]

Parents of children with ASD engage certain coping mechanisms in order to tide through the various phases of development. The previous research has evaluated the role of coping styles employed by caregivers as a protective and remedial mechanism. Parental coping styles and the presence of social support in relationship with developmental disabilities can impact the level of parental distress.[23] Higher levels of problem-focused coping and lower levels of emotion-focused coping were generally associated with better maternal wellbeing, regardless of the level of symptomatology of the children with ASD.[24] On the other hand, parenting stress was negatively correlated with the engagement coping and social functional support reported by the mothers.[7]

Quality of life (QOL) is defined as an individual's perception about his/her position in life in the context of their culture and value system in relation to their objectives, expectations, standards, and concerns.[25] Due to high-stress levels and associated psychiatric comorbidities, caregivers of children with ASD tend to have a poor QOL.[26] The presence of parental psychopathology and stress can impair the quality of inputs given, thereby hindering progress in the child with ASD. As the role of parents is crucial in the process of development, an understanding of the mental health difficulties, quality of life, and coping styles of parents can give a better understanding of the possible barriers in the process of change. With this background, the current study was planned. Lack of acceptance and awareness are again factors which can hinder the initiation and progress in training. In order to understand this further, the investigators also explored the differences between the maternal estimate and the actual social age of the child. This study extends earlier research by examining the mental health of caregivers of children with ASD. In the Indian setting, limited research has been carried out exploring the coping styles and resultant quality of life of mothers of children with ASD. Thus, the present study aimed to evaluate the coping styles, quality of life, and presence of depressive, anxiety, and stress symptoms in mothers of children with ASD.

MATERIALS AND METHODS

The study protocol was approved by the Institutional Human Ethics Committee (IHEC).

Participants

The sample for this study was selected by consecutive sampling from the psychiatry outpatient department of a tertiary care hospital in south India. The sample was selected from mothers of children (age range of children: 3 to 15 years) who had approached the outpatient department either on their own or through a referral from school, workplace, or other medical professionals for the purpose of assessment and diagnosis. The diagnosis of ASD was made based on (1) clinical interview and detailed evaluation by a qualified psychiatrist and (2) assessment score

obtained on Childhood Autism Rating Scale (CARS) by a qualified clinical psychologist. For assessing the severity of deficits in social functioning, the Vineland Social Maturity Scale (VSMS) was also administered.

Materials

Depression, anxiety, and stress scale (DASS 21)[27] is a 42-item questionnaire to assess symptoms of depression, anxiety, and stress among various populations, age-groups, and clinical and nonclinical respondents. DASS includes three self-report scales designed to measure the negative emotional states of depression, anxiety, and stress. The reliability and validity of the DASS have been established in clinical and nonclinical populations[28,29] DASS has been manually translated into Tamil and back-translated into English for determining the linguistic validity of the translated version. This version has been used in a previous study[30] and the inter-rater reliability was found to be high [$\kappa = 0.68$ ($P < 0.001$), 95% CI (0.504, 0.848)]. As the primary language of the participants in the present study was Tamil, the Tamil version of DASS was used.

WHO quality of life scale (WHOQOL-BREF)[25] is a measure of QOL, which could be reliably used across different cultures. It brings forth the person's perception of life with regard to his/her cultural background and taking into consideration his/her personal goals and standards. It covers four domains: physical, psychological, social, and environmental. The brief version, consisting of 26 items, was used for the present study. The mean scores are calculated separately for each of the four domains.

COPE inventory[31] is a multidimensional coping inventory to assess the different ways in which people respond to stress. It consists of 60 items, divided into 13 scales (four items in each scale), which measure conceptually distinct aspects of coping, namely, active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support, seeking of emotional social support, positive reinterpretation and growth, acceptance, denial, turning to religion, focus on and venting of emotions, behavioral disengagement, and mental disengagement. The participants were instructed to respond to a series of statements, based on how they would react when experiencing stress. These statements described various coping strategies using a 4-point scale: 1 = "*I usually do not do this at all,*" 2 = "*I usually do this a little bit,*" 3 = "*I usually do this a medium amount,*" and 4 = "*I usually do this a lot*." Possible values for each coping scale ranged from 0 to 12, with a higher score indicating greater use of that coping strategy. Cronbach's alpha reliability coefficients for the coping scales ranged from 0.56 to 0.88.

Consistent with the previous research on caregiver coping styles,[32,33] the following four of the original 13 scales were selected as predictor variables in the main analysis for the present study: positive reinterpretation and growth, religious coping, mental disengagement, and behavioral disengagement. Positive reinterpretation and growth involves reframing a problem in a positive light or restructuring a stressful situation in positive terms (e.g., "*I look for something good in what is happening*"). Religious coping refers to turning to faith for support (e.g., "*I put my trust in God*"). Mental disengagement refers to efforts to distract self from thinking about the problem (e.g., "*I turn to work or other substitute activities to take my mind off things*"). Behavioral disengagement involves reducing one's efforts to deal with a particular stressor (e.g., "*I give up the attempt to get what I want*"). As the primary language of the participants was Tamil, this scale was translated into Tamil and back-translated into English for determining the linguistic validity of the translated version.

Procedure

The researcher was trained in the administration of the questionnaires and conducted five interview sessions under the supervision of a clinical psychologist, following which data collection for the present study was started.

The researcher explained the purpose of the study and assured confidentiality to the mothers of children with ASD, and written informed consent was taken. DASS, WHO-QOL questionnaire, and COPE Inventory were then administered to the mothers. The average time taken for the administration of the tools was 25 min. Following the assessment, mothers who were assessed to have high levels of depression, anxiety, or stress symptoms were referred to the psychiatry outpatient department for detailed evaluation by a psychiatrist and for planning further management of the same.

Analyses

Statistical Package for Social Sciences-Version 19 b(SPSS-19) was used for the analyses. The data was found to be normally distributed. Descriptive statistics was used for the analysis of data obtained from the sociodemographic sheet, DASS, and COPE. Independent sample *t*-test was used to determine the difference between the maternal social age estimate and the actual social age of the child. Pearson product-moment correlation was used to test the relationship between the different domains of quality of life and the relationship between levels of depression, anxiety, and stress with QOL and maternal social age estimate.

RESULTS

Sociodemographic characteristics

The sample consisted of thirty mothers of children with ASD. Ninety percent of the mothers were homemakers. All the mothers were literate, with 50% being graduates, and 50% had completed 10 years of formal school education. The mean age of the mothers at the time of childbirth was 25.40 years (SD = 2.95).

The mean score of autism severity was 30 (SD = 3.99), indicating a mild level of ASD. The mean duration of schooling of the children was 2.57 (SD = 1.87) two years. The sociodemographic details are presented in Table 1. History of feeding difficulty was present in 36.6% of the children.

Social age and maternal estimate

The mean social quotient of the children was 51.86 (SD = 29.0), indicating mild disability of social functioning. When the maternal estimate of the child's social age was explored, eight (27%) had overestimated and four (13%) had underestimated the child's social age by 1 year. Independent sample *t*-test indicated that there was no significant difference between the mean maternal estimate of the child's social age (M = 38.4; SD = 16.92 months) and the mean actual social age [(M = 41.37; SD = 24.94 months), t (29) =0.087]. There was no significant correlation between the maternal estimate of the child's social age and the severity of the mothers' depressive (r = -.185, n = 30, P = 0.329), anxiety (r = -.233, n = 14, P =.215), or stress (r = -.134, n = 14, P =.479) symptoms.

Depression, anxiety, and stress symptoms

It was found that 60.4% of the mothers had depressive symptoms, among whom 42.9% reported mild-to-moderate depressive symptoms, while 16.5% had severe depressive symptoms. In addition, 46.2% of the mothers were found to have anxiety, among whom 16.5% exhibited severe anxiety [Table 2].

Quality of life

Among the various domains of QOL, mothers perceived the highest level of QOL in the environmental domain, with a mean score of 73.5, and the psychological domain was the lowest at 65.6. The physical and social relationship domains were intermediate, with mean scores of 72.5 and 69.6, respectively. There was a significant correlation between the domains of QOL. It was also found that the level of QOL in all the domains was negatively correlated with the severity of stress and depressive symptoms [Table 3].

Coping styles

The major coping styles adopted by the mothers included active coping, positive reframing, planning, acceptance, and religious coping [Table 4].

DISCUSSION

The earliest phase of the child's life was a period of relative normalcy and social cohesion. In the second phase, the child's behaviors began to disrupt the everyday social order, but parents viewed these unexpected behaviors as temporary. In the third phase, parents' observations in public situations, along with assessments of others, led to a qualitative shift in which

Table 1: Sociodemographic characteristics (*n*=30)

Variable	*n*	%
Age (Mean±SD)	6.5±4.5 yrs	-
Gender (Male)	25	83.5
Consanguinity present	9	30
Autism Severity		
Mild	14	46.7
Moderate	14	46.7
Severe	2	6.7
Education		
Not attending	7	23.1
Attending school	22	75.9
Special education	17	56.1

Table 2: Depression anxiety and stress levels of mothers

DASS Score range	Depression (%)	Anxiety (%)	Stress (%)
Normal	39.6	52.8	52.8
Mild	19.8	16.5	26.4
Moderate	23.1	13.2	16.5
Severe	9.9	9.9	0
Extremely Severe	6.6	6.6	3.3
Mean Score (±SD)	6.13 (±3.82)	4.0 (±3.38)	6.8 (±4.12)

DASS: Depression Anxiety Stress Scale

Table 3: Correlation between QOL and DASS scores

Domain	Depression	Anxiety	Stress
Physical	-0.38* (*P*=0.037)	-0.53** (*P*=0.002)	-0.45* (*P*=0.014)
Psychological	-0.73** (*P*=0.001)	-0.35 (*P*=0.055)	-0.69** (*P*=0.001)
Social	-0.53** (*P*=0.003)	-0.29 (*P*=0.124)	-0.51** (*P*=0.004)
Environment	-0.48** (*P*=0.007)	-0.32 (*P*=0.083)	-0.54** (*P*=0.002)

*Correlation is significant at 0.05 level (2-tailed). **Correlation is significant at 0.01 level (2-tailed). DASS: Depression Anxiety Stress Scale. QOL: Quality of Life

Table 4: Coping styles followed by mothers

Coping Style	*n*	%
Active coping	11	38.3
Positive reframing	11	38.3
Planning	9	38.3
Acceptance	12	36.65
Religion	10	38.3

parents began to perceive that there was a persisting problem interfering with their child's social and practical activities. In the fourth phase, parents grappled with developing their child's capacities to meet existing practical opportunities in the local society.

Caregivers of individuals with disabilities are at high risk for psychological distress because of the multiple stressors known to be associated with the caregiving role.[34] In the current study, a majority of the children had mild severity levels of ASD as well as disability in social functioning, resulting in a delay in the development of social skills. This indicates the extent of increased workload and stress that mothers would experience as part of their caretaking role.

These findings are comparable to the previous research findings, which have also emphasized the long-standing stress experienced by the caregivers due to physical and emotional strain, lack of support from other family members, and gradual progress in the child, thereby making them more prone to mental health difficulties.[35]

Only after awareness and acceptance that a child has ASD, the caregiver would proceed to the next stage of training and skill development. When a caregiver is unaware or refuses to accept the child's diagnosis of ASD, it results in a delay in the initiation and regularity of intervention. A majority (46.2%) of the mothers had correctly estimated their child's social age in the present study. Twenty percent of mothers had overestimated their child's social age by more than one and a half years and 6.6% of mothers had underestimated their child's social age by more than one and a half years. There was no significant correlation between this difference in the maternal estimate of the child's social age with the mothers' quality of life, depression, anxiety, or stress levels.

With regard to education and training, more than half of the children with ASD were attending special schools/training centers. These two factors, namely, the high percentage of mothers who correctly estimated their child's social age and placement in special schools/training centers, reflect the increased level of awareness among mothers about the child's deficits as well as the need for special training. This awareness was indicated in another study, where the major symptom identified by the majority of the parents was social difficulty among their children.[36]

The high level of depressive and anxiety symptoms seen in the present study is consistent with the previous research, which has emphasized the long-standing stress experienced by caregivers due to physical and emotional strain, lack of support from other family members, and a gradual deterioration in the child, which makes them more prone to develop a psychiatric illness.[37] This is also reflected by higher levels of depressive and anxiety symptoms in caregivers assessed in similar studies.[38] This implies that more attention has to be paid to the mental health of parents, particularly mothers, of children with ASD.

It was also found that almost half of the mothers in the study were experiencing stress. A study on parenting stress in mothers of children with ASD reported behavioral symptoms as the primary source of parenting stress for mothers. Mothers reporting more parenting stress had more depressive symptoms and lower levels of well-being.[39]

QOL was found to be impaired, primarily in the psychological, social, and environmental domains. These findings are comparable to a study on the impairment of QOL in parents of children and adolescents with ASD that used the same scale. When compared to parents of healthy children, parents of children with ASD reported impairment in physical activity, social relationships, and worse overall perception of their QOL and health. The impairment of physical and psychological well being was more in mothers when compared to the fathers in the ASD.[43] Parents of children with ASD experience a higher burden, probably due to a combination of environmental and physical factors. In the present study, all four domains of QOL had a negative correlation with depression and stress symptoms. This was similarly seen in a previous study on depression and QOL in mothers of children with ASD, where it was found that QOL had a negative association with depression.[40]

The previous research has evaluated the role of coping styles employed by caregivers as a protective and remedial mechanism. Parental coping styles and the presence of social support in relationship with developmental disabilities can impact the level of parental distress.[23] An interesting finding in the present study is that the mothers had impaired QOL as well as high levels of depressive and stress symptoms. In spite of this, they predominantly followed positive coping styles. Problem-focused coping or active coping is the process of taking active steps to try to remove or circumvent the stressor and its effects. A positive attitude among the mothers was reflected through their employment of positive coping strategies. The least employed coping styles were substance use, denial, venting, and self-blame. Taylor, in 1983, had proposed a theory of cognitive adaptation which may help to interpret the results reported in this study. Among the factors that account for recovery from stressful events, two stood

out as particularly important: a search for meaning in the experience and an attempt to regain mastery over the situation.[41] In support of this perspective, the present study indicates the use of the coping style of positive reframing for overcoming and adapting to their current difficult situation. Similarly, the previous research has also shown an inverse relationship between psychological stress and positive coping strategies, in which the use of positive reinterpretation and growth was associated with lower levels of depression and stress symptoms.[33,42]

In the present study, religious coping was seen to be more commonly employed as compared to other coping styles. This is in line with the previous research in India in which caregivers reported that their religious practice gave them peace of mind and helped them to endure the caregiving situation[43] and that the most common coping style used by mothers of children with intellectual disability was religious coping.[44]

Limitations were present in the current study. The first limitation was that the sample size was small and restricted to hospital outpatient participants. A larger sample size and inclusion of a community-based sample could have improved the generalizability of the findings. The second limitation was that the psychological status of the mothers prior to the diagnosis of ASD and the presence of ongoing life stressors were not addressed. Third, the presence of comorbid attention deficit hyperactivity disorder (ADHD) in the children with ASD could have also influenced the current findings, as past research has shown that the presence of ASD with comorbid behavioral problems increases the level of parental stress.[24] A fourth limitation was the cross-sectional study design. A longitudinal design could have tapped deficits across the lifespan. Future research can compare the severity of psychological distress with the duration after diagnosis of ASD and the life stage of the child (early childhood, later childhood, early adolescence), as the needs and parental expectations vary at each stage. In this context, yet another lacuna to be pointed out is the limitation of the tool used in the present study that assesses depressive, anxiety, and stress symptoms experienced within the period of one week prior to the interview, which could have been situational. A detailed clinical assessment would also be required to establish a diagnosis of depression and anxiety and offer treatment for the same. Future studies can also look into follow-up assessment after the implementation of appropriate psychoeducational interventions.

Nevertheless, the study results highlight the often-neglected difficulties and psychological distress encountered by the caregivers of children with ASD, which require multi-modal interventions. The caregiver may not have the capacity to change the situation, but appropriate use of coping strategies will result in stress reduction and improved functioning, thereby resulting in a better quality of care. The role of parents, as well as persistence and consistency in parental engagement and training, is crucial for the overall development of the child. Research has indicated the effectiveness of a parent-mediated communication-focused intervention in ASD.[29] Positive mental health among mothers is crucial for their adequate involvement and care delivery for children with ASD.

CONCLUSION

The present study indicates the presence of depressive, anxiety, and stress symptoms among the mothers of children with ASD, as assessed on the DASS 21. The QOL of the mothers was found to be impaired, as per assessment on the WHO-QOL. In spite of having high levels of symptoms of depressive, anxiety, and stress symptoms, the mothers predominantly adopted positive coping styles, namely, active coping, positive reframing, planning, acceptance, and religious coping.

The insights obtained from this study extend previous findings that mothers of children are at increased risk of developing psychiatric distress, a fact which frequently goes unrecognized and less addressed when planning the long-term management for children with ASD.

Promoting the best QOL possible for mothers of children with ASD requires significant time and attention to both individual- and family-based needs. For many of these families, substantial specialized care and resources are needed across the lifespan of the individual with ASD. The treatment process can include a component of addressing the parental stress, which in turn will help optimize treatment outcomes for the child and the family.[19]

The implication of this study is to emphasize the role of mental health providers for adequate care delivery for the parents, along with the children with ASD. Regardless of the attitude or acceptance of the caregiving role, it is important to value and respect the individual mental health and coping styles of the parent. Comprehensive mental health care can include screening parents for psychological distress, psychoeducation regarding the appropriate use of coping styles for managing distress, peer support, and provision of support for parents of children with ASD.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

The Impact of Autism Spectrum Disorder in Comparison with Other Neuro-Developmental Disorders in Children on the Family: Single Centre Experience

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ABSTRACT

Background: Neurodevelopmental disorders (NDD), especially autism spectrum disorder (ASD), have a substantial impact on the family, with a consequent decrease in the quality of life. The current study was undertaken to understand if having ASD contributed to a higher impact on families compared to other NDD and to understand additional factors impacting families of children with either disorder in a low-middle income country (LMIC) setting. **Methods:** Impact of ASD and other NDD along with sociodemographic factors was examined, by a retrospective analysis, among 540 children in a tertiary care center in South India. **Results:** Both ASD and NDD had high, but comparable, impact on the family. Being a girl child, having seizures, and having sleep problems predicted a higher impact. **Conclusions:** In children with NDD, managing co-morbidities such as achieving better seizure control and addressing sleep-related problems may improve the impact of NDD on the family. Gender disparity in disability needs to be studied within the local cultural context.

Key words: *Autism spectrum disorders, children, impact on family, neurodevelopmental disorders*

Key messages:

- Autism spectrum disorder and neurodevelopmental disorders had high, but comparable, impact on the family.
- Being a girl child or having comorbid epilepsy or sleep problems had a higher impact on the family.
- Early identification and appropriate interventions of the comorbid problems are necessary in children with neurodevelopmental disorders.

Neurodevelopmental disorders (NDD), including autism spectrum disorder (ASD), have a multi-faceted impact on the family, including restriction of parental

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time and occupation, family and societal relationships. They also affect the physical as well as psychological well-being of the family members and cause a significant financial burden.[1] Raising a child with NDD contributes to an increase in parental mental health problems and parental stress with a decrease in well-being and quality of life.[2] ASD is reported to have a higher impact than other NDD, probably due to the pervasive nature of ASD along with limited services and support systems for these families in comparison to other NDD such as cerebral palsy.[3-6] Compared to high-income countries, care and support systems for all NDD are still only evolving in the low-middle income countries (LMIC), compounding their overall impact on the families. NDD, including ASD, have a high impact on families in the LMIC, resonating similar trends across the world.[7-14] The current study was undertaken to understand if having ASD contributed to a higher impact on families compared to other neurodevelopmental disorders and to understand additional factors impacting families of children with either condition in a LMIC setting.

METHODS

The present retrospective study was conducted using the inpatient database of all children admitted to a residential facility attached to the Developmental Paediatrics Unit in a tertiary care center in South India from 1st January 2015 to 31st December 2016, i.e., over 2 years. Each child was diagnosed and interventions planned by a multidisciplinary team of developmental pediatricians, psychologists, and therapists. The ASD diagnosis was confirmed by Diagnostic and Statistical Manual of Mental Disorders-fifth edition (DSM-5) diagnostic criteria and Childhood Autism Rating Scale-Second edition (CARS-2). The current study was approved by the institutional review board. All families, on admission, had given the written consent for anonymized data to be used for annual statistics and research. Information about all children admitted is kept in an anonymized departmental database for annual statistical analysis and is password protected.

Measures

All children admitted to the inpatient facility underwent a detailed history taking and neuro-developmental examination. Separate single item questions were asked to the parents about the presence of seizures and sleep and feeding problems as part of the standard co-morbidity questionnaire (developed in the Developmental Paediatrics Unit) administered to all children who visit the Unit. Information about socioeconomic factors, such as maternal and paternal education and employment, were also collected. The developmental assessment was done for all children by trained clinical psychologists, using Griffith Mental Developmental Scale (GMDS), and adaptive skills were assessed using Vineland Adaptive Behavior Scales or Vineland Social Maturity Scale (VSMS).

Vineland Adaptive Behavior Scales-Second Edition was used to assess adaptive behavior in four domains: communication, daily living skills, socialization, and motor skills. It provides standard scores in each of the domains and an overall adaptive behavior composite. Lower scores indicate greater impairment in adaptive functioning.[15]

VSMS estimates the social age (SA) and social quotient (SQ) and the score shows a high correlation (0.80) with intelligence. It is designed to measure social maturation in eight social areas: self-help general (SHG), self-help eating (SHE), self-help dressing (SHD), self-direction (SD), occupation (OCC), communication (COM), locomotion (LOM), and socialization (SOC). The scale consists of 89 test items grouped into year levels. It can be used for the age group of 0–15 years.[16]

GMDS is used to assess the development of a child from 0 to 8 years across six separate subscales: locomotor, personal-social, language, eye-hand co-ordination, performance, and practical reasoning.[17]

Childhood Autism Rating Scale-Second Version (CARS-2) was scored for all children with ASD. This behavioral rating measure is used to identify children with autism and rates the severity of their behavior using 15 items, with the final score ranging between 15 and 60.[18]

Other informal assessments developed by the Unit were also used to monitor play, behavior, and social interaction. Global developmental delay was considered if there were deficits in more than two domains of development, including fine motor skills, language, social skills, and cognition.

The revised Impact on Family Scale (IOF) was used to assess parents' perceptions about the impact on the family and has 15 items and one factor. Parents can rate each item on a four-point Likert scale as 1–"strongly agree"; 2–"agree"; 3–"disagree"; or 4–"strongly disagree" with the items reverse scored as necessary. The scale has acceptable reliability and validity.[19,20] It is routinely administered to all families in the inpatient setting to assess the impact of NDD and to provide appropriate support. Parents who could understand English completed the questionnaire by self, while others used the help of one of the investigators. An item score of >1 and a total score >15 are considered

to indicate an impact on the family.[19,20] For analysis, missing values were excluded from the final analysis. The IOF score was taken as a categorical variable, with values above the 66th centile considered as high impact and the ones below, low impact. Bivariate analysis was done between the IOF score and the diagnosis to evaluate the odds ratio with a 95% confidence interval. Further, a multivariate logistic regression was done, adjusting for other variables such as sex, age, presence of developmental delay, paternal and maternal education, and co-morbidities such as seizures, sleep problems, and feeding problems.

RESULTS

The study group had 540 children, with a male preponderance [Table 1]. The group consisted mainly of higher educated mothers and fathers with either a graduate or postgraduate degree. 45.2% of children had a diagnosis of ASD, while the diagnosis of other NDD, including cerebral palsy (CP), dysmorphic states, and specific language disorders accounted for the rest. Two children had a co-existing diagnosis of CP and ASD. The majority of children had developmental delays, and approximately a fourth had seizures. Sleep and feeding problems were present in 25.1% and 12.2%, respectively. Incomplete IOF forms were found in 51 children and were excluded from the final analysis.

All families reported a high impact with a mean (±SD) of 38.14 (±11.0). All items of the impact questionnaire had a comparable impact on both ASD and other NDD. Both sets of parents reported "being tired" as the highest impact item.

There was no significant difference between the impact of ASD and other NDD [OR (odds ratio): 1.08, Table 2]. Being a girl child (OR: 1.69) and associated problems such as seizures (OR: 2.60) and sleep problems (OR: 1.70) predicted a higher impact on family, which remained significant in multivariate logistic regression.

DISCUSSION

The impact of NDD, including ASD, in different cultural contexts needs to be evaluated not only to understand the spectra of influences of these conditions but also to devise culture-specific measures to modulate their impact. The main objective of this study was to understand the factors that impact Indian families of children with either ASD or NDD and to explore whether this impact differed for each of these conditions. Current reviews on the impact on families of children with NDD have predominantly covered research from high-income countries and reported higher stress for parents of children with ASD than those with other NDD.[6,21] Subsequent studies after the reviews have also confirmed that parental stress is higher in ASD compared to children with developmental delay or typically developing children.[22,23]

Table 1: Demographic characteristics of the study group (*n*=540)

Variable	Category	*n* (%)
Gender	Boys	398 (73.7%)
	Girls	142 (26.3%)
Diagnosis #	ASD:	244 (45.2%)
	Others:	294 (54.4%)
Age	≤5 years	408 (75.6%)
	>5 years	132 (24.4%)
Development (%)	Global delay	510 (94.4%)
	No global delay	30 (5.6%)
Seizures (%)	Absent	396 (73.3%)
	Present	144 (26.7%)
Sleep problems (%)*	Absent	404 (74.8%)
	Present	135 (25.0%)
Feeding problems	Absent	474 (87.8%)
	Present	66 (12.2%)
Maternal education**	≥Graduate	337 (62.4%)
	Lower	193 (35.7%)
Paternal education**	≥Graduate	342 (63.3%)
	Lower	188 (34.8%)

#2 children had cerebral palsy and ASD. *1 missing value. **10 missing values. ASD–Autism spectrum disorder

Literature from India has reported that families of children with NDD show higher financial problems and parental health concerns; decreased social relationships, social support, and quality of life; and increased worry for the future of the affected child.[10,11] Though limited facilities available for children with NDD remain a concern across the studies, a few have highlighted the cultural burden for parents of a child with NDD in the LMIC: These include, but are not limited to, parental guilt, generalized perception of parental "bad karma" or the punishment of God responsible for the disability, blame on the mother, and societal exclusion.[8,9]

Studies have shown multi-dimensional impact of ASD, including occupation discontinuation and personal time constraints on parents. Several unmet needs, with sub-optimal service provisions, were compounded by a low awareness of the society, a negative outlook toward disability, and stigma and discrimination.[24-26] The parental and family adaptation and coping to disability are aided by positive supportive family and social environs, including sociocultural factors.[26] Religion and spirituality can aid in this coping process in multi-cultural societies such as that of India.[13]

Our current study, though observational, is the first quantitative study from India analyzing the impact

Table 2: Risk factors for high impact on family of children with neurodevelopmental disorders

Risk factor	Impact of family		Unadjusted OR (95% CI)	Adjusted OR (95% CI)
	High impact No. (%) (*n*=159)	Low impact No. (%) (*n*=328)		
Females	53 (33.3%)	75 (22.9%)	1.69 (1.11-2.56)*	1.67 (1.09-2.59)#
ASD	64 (40.3%)	158 (48.1%)	0.72 (0.49-1.07)	1.08 (0.68-1.70)
Older age	41 (25.8%)	76 (23.2)	1.15 (0.74-1.78)	0.99 (0.60-1.63)
Developmental delay	152 (95.6%)	311 (94.8%)	1.19 (0.48-2.92)	0.95 (0.33-2.69)
Seizures	63 (39.6%)	66 (20.1%)	2.60 (1.71-3.95)*	2.49 (1.55-3.98)#
Sleep problems	52 (32.7%)	73 (22.3%)	1.70 (1.11-2.59)*	1.63 (1.02-2.60)#
Feeding problems	21 (13.2%)	37 (11.3%)	1.19 (0.68-2.12)	0.85 (0.45-1.61)
Higher maternal education	92 (57.9%)	198 (60.4%)	0.85 (0.57-1.29)	0.85 (0.51-1.42)
Higher paternal education	104 (65.4%)	206 (62.8%)	1.09 (0.71-1.65)	1.34 (0.80-2.26)

OR - Odds ratio, ASD–Autism spectrum disorder. *$P<0.05$, Bivariate analysis, #$P<0.05$

of ASD along with that of other NDD. The finding of comparable high impact of both ASD and NDD in our study, unlike the findings from high-income countries, might be related to sub-optimal service provisions for both the conditions in the LMIC setting. Resources, awareness, facilities for early diagnosis, and interventions for other NDD are available and accessible in most high-income countries. The evolving status of definition, diagnosis, and interventions for ASD, along with the requirements of highly intensive therapy, might add additional stressors for families of children with ASD in such settings.[27,28] Service provisions for all NDD are in a preliminary state in India, leading to the finding of a uniformly high impact on the families.

Parents of girls from either group reported a higher impact than parents of boys. The gender disparity of favoring a boy child has been prevalent in many sociocultural contexts in India, starts even before birth, and is mirrored in the current analysis of the impact on the family.[29] The discrimination against girls is reflected in both the smaller number of girls seeking medical attention and intervention compared to boys in our study as well as being a girl considered a significant factor for impact on families.

Comorbid medical and psychological problems can worsen the impact of NDD.[3] In the current study, the presence of seizures predicted a higher impact on the family, as is documented in other studies.[30,31] Caring for a person with seizures/epilepsy can be challenging in terms of acute care during an episode as well as daily prophylactic medications. Moreover, the presence of seizures can indicate a higher severity of the condition, such as in the case of cerebral palsy, which also contributes to a higher impact.[30] Sleep problems in children with NDD can impact the child's behaviors and academic achievement as well as parental sleep patterns, thus affecting the overall quality of life of the family. The high impact of sleep problems as reported in the current study is in line with the existing literature.[32,33] In our study, the presence of developmental delay did not predict a higher impact on the family, which is contradictory to available reports.[28,34] This might probably be due to a high percentage of children with global developmental delay in the inpatient population in this analysis.

There are limitations to this study, including it being an observational retrospective analysis done in a tertiary care center. There can be questions raised about the generalizability of study findings. However, this study highlights the high and comparable impact of both ASD and NDD in the LMIC setting and brings to the fore sociocultural factors such as gender disparity. Future neuro-developmental studies in India need to incorporate local cultural factors for better understanding. This study also highlights that clinicians taking care of children with NDD should evaluate and manage co-morbidities because additional co-existing conditions can impact families. Optimal management of co-morbidities, such as seizure control and ensuring better sleep quality, using either non-pharmacological or pharmacological measures, can improve the overall quality of life of the family.

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Conflicts of interest
There are no conflicts of interest.

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Original Article

Development of a Battery to Assess Perceptual-Motor, Cognition, Language, and Scholastic Skills among Bengali Children with Neuro Developmental Disorders

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ABSTRACT

Background: School failure or poor academic performance is often found in neurodevelopmental disorders (NDD); however, there is a dearth of a comprehensive assessment tool to evaluate various underlying deficits, including perceptual-motor, cognitive, language, and scholastic skills of those who have NDD. The study aimed to develop a test to fill-up this gap. **Materials and Methods:** The study followed three phases: the construction of an assessment battery in both Bengali and English languages, separately, incorporating tasks on perceptual-motor, cognitive, language, and scholastic skills; doing a pilot study, and finally, standardization. Standardization was done on 91 normal children (NC) aged 4.5 to 9.5 years, from four districts of West Bengal. The test was applied to 57 children with poor school performance across various NDD, including specific learning disorder, autism spectrum disorder, attention deficit/hyperactivity disorder, and communication disorder. Binet Kamat Test (BKT) of intelligence, National Institute of Mental Health and Neuro-Sciences (NIMHANS) Index for specific learning disability (SLD), Childhood Autism Rating Scale (CARS), Conner's Abbreviated Rating Scale- Parent Report, Linguistic Profile Test, and Test of Pragmatic Language were used as screening tools to identify children with various NDD. The psychometric properties of the tool were assessed. **Results**: The factor analysis suggested four-factor solution named scholastic–cognitive–motor, attention, auditory–verbal, and perceptual skill. The internal consistency of the test was found to be higher (Cronbach's $\alpha > 0.70$ for most tests), indicating high reliability. Discriminant validity revealed significant score differences between NC and children with NDD ($P < .01$), suggesting that the new tool can differentiate children with NDD from healthy NC. **Conclusion:** The results favor the new tool as a psychometrically strong

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tool to assess the scholastic backwardness of children with NDD. It may be further used to create specific profiles for different categories of NDD.

Key words: *Assessment battery, cognition, language, perceptual-motor skills, scholastic backwardness*

Key messages:

- *There is a dearth of a comprehensive battery that identifies scholastic backwardness from the information-processing perspective of children having NDD.*
- *A new, culturally sound battery is introduced with acceptable reliability and validity, which may be of help to identify the nature of specific deficits in NDD and to plan intervention.*

A congenial and stimulating environment, age-appropriate emotional wellbeing, and sensory, motor, cognitive, and linguistic skills are primary prerequisites for a child to acquire literacy and successfully finish schooling. In India, children dropping out of school is a frequent phenomenon, of which some are because of inadequate ability to acquire scholastic skills (e.g., reading, comprehension (COM), written expression, computation, etc.). Assessment or intervention for these school dropouts is still an uphill task and it is furthermore difficult for the students with neurodevelopmental disorders(NDD). Research has shown that a complex network of neural pathways is responsible for learning.[1,2] Even a minimal disruption in this mechanism shows up as an impairment, disability, disorder, or difficulty in a given function. The fifth edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5)[3] categorizes such deficits among young children under NDD, like, autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), communication disorder (CD), specific learning disorder (SLD), and intellectual developmental disorder. These conditions often lead to scholastic difficulties, emotional problems, school truancy, and low self-esteem.[4]

Today, the revised Rights of Persons with Disabilities (PWD) Act, 2016[5] is a step to identify and help such children to cope in life; however, unavailability of one standardized tool suitable across the different mediums of school instruction is a major hurdle in evaluating the NDD children with scholastic difficulties. Unfortunately, there is a dearth of a comprehensive psychological assessment tool that may be used across most NDD without intellectual disability to identify kinds of underlying deficits in various domains, including academics. Clinicians choose tests from existing test batteries and translate test items to their regional language. As a result, it might be difficult to get a uniform report that would help decide a management plan. All these necessitate the development of a comprehensive test battery comprising of various faculties, including perceptual, cognitive, language, and scholastic skills.

Difficulties in scholastic skills (like reading, COM, expression, writing, spelling [SPL], and mathematics) associated with various NDDs can be the result of a deficit in one or more processes of learning.[6] The acquisition of these skills requires the brain to process multimodal information in different parts of the brain that constitute the information processing model for mental development.[7] This theory attempts to describe how sensory input is perceived, transformed, reduced, elaborated, stored, retrieved, and used by the human mind. It includes attention mechanisms for bringing in information, working memory for actively manipulating information, and long-term memory for passively holding information so that it can be used in the future.[8]

Identifying the deficits in mechanisms underlying information processing can help in better intervention planning to improve performance and increase self- esteem.[9] Most of these findings have been established in western countries on tools standardized on their populations. Some of the tests that are developed in India to tap down many of the above-mentioned functions, like the National Institute of Mental Health and Neuro-Sciences (NIMHANS) Index for SLD, lack originality and are specially designed for a specific NDD group. Moreover, language skill is one important domain in scholastic skills, and it is absent from this tool. Keeping this in mind and considering the heterogeneity of NDD, the current study was conceptualized with the aim to develop an assessment tool to cater to difficulties in learning the scholastic skills among Bengali children with NDD attending Bengali or English medium schools. In addition, it would be more beneficial with respect to interventions if detection of the problems were done at the preprimary level, which is often not covered in most of the existing tests like the diagnostic test of learning disability (DTLD).

MATERIALS AND METHODS

Study design

This study involved three phases, including test construction, pilot study, and standardization. The study was carried out over a period of 5 years from 2012 to 2017 (Phase I- 2 years; Phase II- 1 year, and Phase III- 2 years). The institutional ethics committee approved the study.

Phase I: Description and preparation of the battery

The objective of this phase was to develop a comprehensive test battery to assess scholastic difficulties in terms of information processing deficits among children with NDD. Reading skill deficits may result from deficits in speech perception[10] or basic auditory processing,[11] poor ocular motor control necessary for spatial coding,[12] or problems in visual attention (VUAT).[13] Likewise, the written expression can be affected by cognition, along with problems in language, reading, SPL, or visuomotor skills. Underlying shortcomings that interfere with handwriting performances are poor motor skills, difficult temperament, faulty visual perception of letters and words, and difficulty in retaining visual impressions.[14] Similarly, mathematical learning incorporates language, conceptual, visual-spatial, and memory abilities. Assessing visual organization and reasoning ability was also necessary for students with learning disorders in mathematics.[15] Keeping these foundations in mind, the domains were planned and the authors prepared the items. The authors also reviewed available tools to formulate some of the tasks for perceptual-motor, cognitive, and language domains. The scholastic skills were selected in terms of common skills that are prerequisites to pursue schooling and the skills included in the curriculum of government-run schools in West Bengal. Each domain has subdomains, as given in Table 1. The application of the tool was initiated with 4 major domains and 32 specific subdomains that identify different dominant functions from the embedded composite. Details of these functions are mentioned in Table 1.

The items of each subdomain were revised to determine the index of discrimination by gradually increasing the difficulty level of the items. The tasks were open-ended, closed-ended, or semi-open ended. The items developed were sent to experts (child psychiatrists, clinical psychologists, speech-language pathologists, special educators, and primary school teachers) to get their ratings with respect to relevance, appropriateness, and difficulty level of the task for the specific domain. Their suggestions were incorporated and the necessary changes made in the items. Reading COM, written expression, and handwriting tasks were dropped as the experts observed a lack of objectivity in the scoring (these three domains have been worked upon in a subsequent study).

The tool was prepared in the form of three booklets:

1. Manual- with instructions on how to execute the tests, answer keys, scoring patterns, identifiers, and codes
2. Stimulus booklet- with all the visual stimuli
3. Response booklet- with all sociodemographics, closed-ended questions, and worksheets.

Phase II: Pilot/Try out phase and establishment of initial validity

The researchers selected four English medium schools where sensitization programs on scholastic difficulties were conducted. Informed consent was taken from the parents of children from classes I to V with the assent of the children to participate in the study. The children with mother tongue as Bengali only were considered. In the pilot phase, five students (both boys and girls), with appreciable academic performance in the school, were selected from each class. Thus, 25 students were administered the assessment battery in a structured environment in 2 to 3 sessions within a span of 2 weeks. Trained clinical psychologists under the supervision of the researchers carried out the assessment. Based on the results of the pilot phase, the object trail task was removed, as it was too easy for almost all children. The difficulty level of some of the tasks was increased. The final tool was then given to their experts including a neuropsychologist, clinical psychologist, and a special educator. The face validity of the tool was found to be adequate.

Phase III: Main phase and standardization

This phase consisted of two parts. In the first part, the goal was to assess the internal consistency of the subscales. Forty school-going children, as per the inclusion and exclusion criteria mentioned below, were assessed on the newly developed tool. Subtests were introduced in the order as it appears in Table 2. An item-total correlation was also calculated to assess the power of each item in the subdomain, and the less powered (Cronbach $\alpha < 0.70$)[18] items were removed.

Details of the second part are mentioned below.

Study population and sample

School-going children from urban and semi-urban areas of West Bengal state covering four districts (Howrah, Kolkata, North, and South 24 Parganas) were considered for this phase. Two English medium schools from each district were approached where the authors had done sensitization seminars for teachers and parents before. Parental consent and assent of children

Table 1: Domains and subdomains of assessment battery and their functional implications

Domains	Subdomains	Functions[16]
Perceptual Motor		
1.	LM*	Gross visuomotor control, monitoring, and learning
2.	SM*	Fine visuomotor control, monitoring, and learning
3.	Visual perceptual and motor integration	Motor control, balancing and response inhibition
4.	Position in space	Orientation to visual space (i.e., perceptual orientation), scanning, visual discrimination, as well as visual identification
5.	Spatial relations	Visuo-motor coordination, visual scanning, and visual serial processing
Cognitive		
1.	Analogy and similarities	Attributional and relational similarity thus measuring verbal concept attainment
2.	VR*	Perceptual reasoning through visual processing of information, identify visual semantic association and concept formation, as well as problem-solving analysis and inferences
3.	Categorization	Relationship between subjects of knowledge. It measures both discrimination and commonality between objects and is associated with conceptual coherence
4.	Object trail	Focused attention
5.	Auditory verbal memory*	A measure of general verbal learning ability. It also assesses AUA and ability to encode, combine store and recover verbal information in different stages of immediate memory
6.	Visual working memory	Ability to work with visual stimuli within short-term memory. It is also a measure of visual mapping
7.	Visual span	VUAT
8.	VSQM*	Recognition of sequence, discrimination of the same, and reproduction of sequence
9.	Visual implicit memory	Perceptual learning task assesses perceptual closure and has been associated with concept formation and perceptual recognition of object
10.	Auditory visual integration	Combining auditory and visual information
11.	AUA*	Sustained attention and discrimination in the auditory modality, as well as assess response disinhibition
12.	VUAT*	Sustained attention and discrimination in the visual modality, as well as assess response disinhibition
Language		
1.	Phonological awareness	Segmenting and identifying the smallest mental unit of the sound in different positions-initial, medial, and ending. It also involves phonological awareness
2.	ACOM*	Assesses receptive knowledge and whether the child is able to follow multistep instruction
3.	ARP*	A task of auditory recognition or COM that involves phonological awareness and syntactical knowledge. It also assesses oro-motor control (i.e., decoding and encoding of an utterance)
4.	PRG*	Measures structural linguistic knowledge and preexisting knowledge. This involves the linguistic encode or meaning of an utterance. It also assesses associative and inferential thinking
5.	Syntax	Involves grammatical and logical order that connects the linguistic meaning with linguistic form
6.	Vocabulary	Assesses word meaning
Scholastic Skills[17]		
1.	NA*	Involves number recognition (symbol mapping), one to one correspondence, counting (boot up), manipulation of numbers, verbal motor match while counting, linear number placement, symbolic, and nonsymbolic matching between symbol and nonsymbol. These involve decomposing, rearranging, and recomposing of numbers
2.	LTR*	Identification of letters after getting auditory information

Contd...

Table 1: Contd...

Domains	Subdomains	Functions[17]
3.	WR*	A task of word recognition skill to assess orthographic adequacy. This also measures memory-based phonological decoding skill and involves simultaneous processing of information
4.	Pseudo WR	Assesses phonological processing awareness or orthographic phonological skill and the ability of decoding script with its conventional sound system
5.	Reading COM*	Assesses both sustained attention and simultaneous processing of words, sentences, and context
6.	QT*	Assesses mathematical awareness and quantifying skills. It involves nonsymbolic and symbolic—numerical capacity of processing, discrimination of numerical quantities, and problem-solving (transcoding)
7.	SPL*	The measure of phonemic awareness and memory. It assesses auditory linguistic retrieval efficiency
8.	Written expression	Organizing thoughts and expressing them in the written mode
9.	Handwriting	Fine-motor coordination

*These tests were finally included in the battery. LM – Large muscle, SM – Small muscle, VR – Visual reasoning, VSQM – Visual sequential memory, AUA – Auditory attention, VUAT – Visual attention, ACOM – Auditory comprehension, ARP – Auditory repetition, PRG – Pragmatics, NA – Numerical ability, LTR – Letter recognition, WR – Word reading, COM – Comprehension, QT – Quantitative thinking, SPL – Spelling

Table 2: Internal consistency of the items within a domain

Sr. No.	Domains	No. of Items	Total Cronbach's α
1	LM	18	0.94
2	SM	7	0.58
3	Spatial relation	9	0.86
4	Visuomotor	9	0.81
5	VSQM	5	0.81
6	Categorization	8	0.82
7	Visual working memory	12	0.75
8	Implicit memory	6	0.89
9	VR	10	0.74
10	Auditory visual integration	4	0.88
11	Analogy and similarities	7	0.82
12	Position in space	17	0.89
13	Visual span	5	0.43
14	NA	31	0.97
15	SPL	28	0.97
16	Letter reading	18	0.99
17	QT	29	0.86
18	WR	42	0.99
19	Pseudo WR	29	0.98
20	Reading COM	24	0.98
21	Phonological awareness	34	0.97
22	ARP	8	0.94
23	Syntax	12	0.80
24	Pragmatix	48	0.88
25	ACOM	3	0.86
26	Vocabulary	28	0.97

LM – Large muscle, SM – Small muscle, VSQM – Visual sequential memory, VR – Visual reasoning, NA – Numerical ability, SPL – Spelling, QT – Quantitative thinking, WR – Word reading, COM – Comprehension, ARP – Auditory repetition, ACOM – Auditory comprehension

could be obtained from 345 students, and they were rated by the respective teachers on Behavioral Checklist for Screening the Learning Disabled (BCSLD) to rule out any form of learning problems. Fifty-two students were not considered as normal control because of elevated score in BCSLD. Out of 293 children without significant learning problems, 100 children ($N_1 = 100$) were randomly selected for further assessment using the newly developed battery.

Sixty children ($N_2 = 60$) with NDD were selected from child development clinics of Kolkata, where representative population from these four districts could be found. Selected categories of NDD were children with Attention Deficit/Hyperactivity Disorder (ADHD), Specific Learning Disorder (SLD), Language Disorder under CD (LD), and Autism Spectrum Disorder (ASD).

Inclusion criteria

Aged 4.5 to 9.5 years, both genders, at least 2 years of schooling, and understands and speaks Bengali and English

Exclusion criteria

For children with NDD: a history of seizure disorder, any sensory impairment, first-generation learner, started schooling after 3 years 6 months of age, and intelligence quotient (IQ) < 90.

For normal children (NC): IQ < 90, in addition to the above conditions.

Materials

- Behavioral checklist for screening the learning disabled (BCSLD)[19]
- Binet Kamat test (BKT) of intelligence[20]
- NIMHANS-SLD[21]
- The Childhood Autism Rating Scale- 2nd Edition (CARS-2)[22]
- Conner's 10 items Abbreviated Rating Scale- Parent Rating (CARS-PR)[23]

- Linguistic Profile Test (LPT)[24]
- Test of Pragmatic Language 2nd Edition (TOPL-2).[25]

Data management

The 60 students with poor academic performance were assessed with BKT, NIMHANS-SLD, CARS-PR, CARS-2, LPT, and TOPL-2 to identify causes of poor scholastic performance and comorbid factors. Of the 100 NC, the total assessment battery could not be completed on nine children. For 60 NDD children, three had to be dropped for having comorbid conditions. Trained clinical psychologists and special educators who were provided special training on assessment assessed the 148 children in various categories on our modified assessment battery. Assessment of each child was done in a structured setting in two to three sessions within a span of 2 weeks.

A schematic diagram of various phases is given in Figure 1.

Data analysis

Statistical calculation was done in the Statistical Package for the Social Sciences (SPSS) software, version 15.[26] Internal consistency was assessed by the item-total correlation of each subdomain. To assess the construct validity, exploratory factor analysis (EFA) through principal component factor analysis (PCFA) was run for 148 children (N_1 + N_2) to identify factor solutions. Domains with low and ambiguous factor loading were excluded to get the final battery. Mean and the standard deviation (SD) was computed for every subdomain. To assess if the normal children had a normal distribution, the Shapiro–Wilk test was run. The student's *t*-test was used to compare the performance of NC and children with NDD across the subdomains.

RESULTS

Table 3 shows the age and gender-wise distribution of NC and children with scholastic problems in different NDD. The NC was divided into five age groups. The lowest group was aged 4.5 to 5.5 years, while age above 8.5 years until 9.5 years was considered as the upper age group. Age and gender-wise distributions were almost equal in the NC group except for the uppermost age group where data were discarded because of missing data. In the NDD

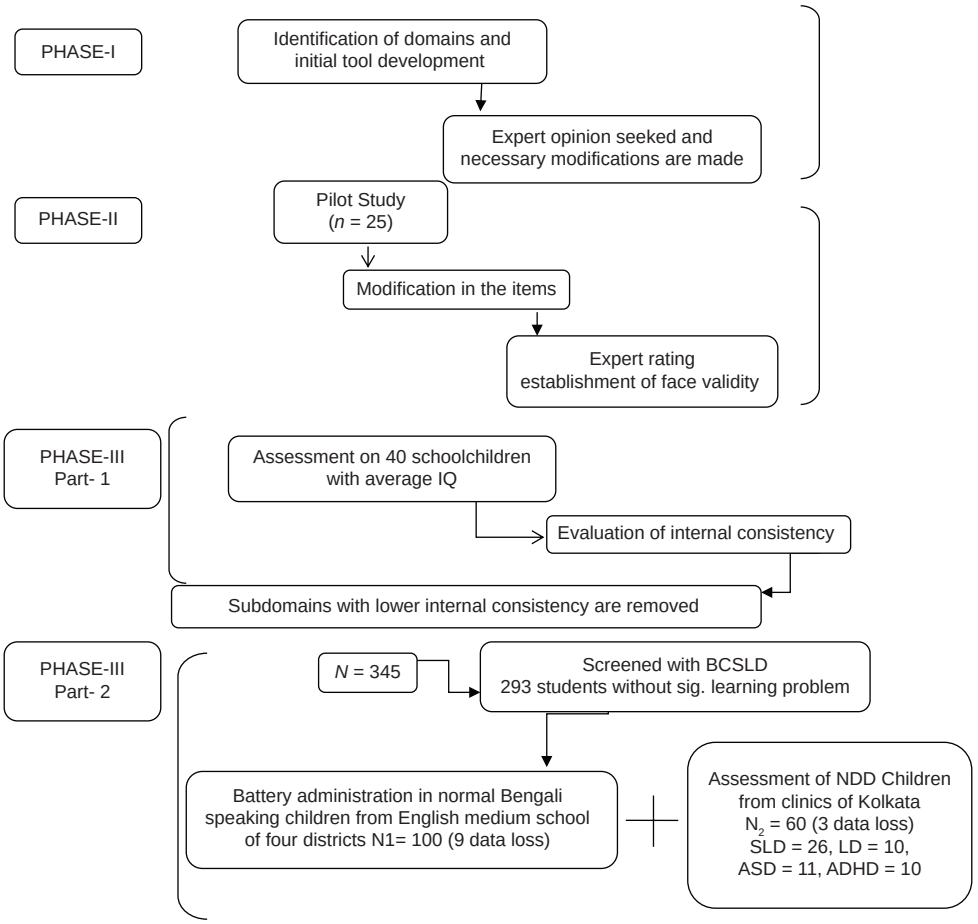

Figure 1: Schematic diagram of the various phases of the tool development. BCSLD = Behavioural checklist for screening the learning disabled, NDD = Neurodevelopmental disorder, SLD = Specific learning disorder, LD = Language disorder; ASD = Autism, ADHD = Attention deficit hyperactive disorder

group, the uppermost age group was underrepresented. Table 3 shows that the gender distribution of NDD children was overrepresented by males (75%).

Table 2 shows the internal consistency of a particular subtest, which is represented as the Cronbach α score. Internal consistency for most of the subdomains was higher than 0.70. The visual span task was found to have poor internal consistency and hence, it was deleted. The small muscle (SM) task had a moderate level of internal consistency, maybe because of the discrete pattern of the items. However, it was retained, as it might be a developmentally appropriate task. For some of the subdomains, it could not be calculated (e.g., auditory verbal learning) as the nature of the task was not with an increasing difficulty level.

As Kaiser–Meyer–Olkin (KMO) measure for sampling adequacy was 0.886 for a sample of 148 and Bartlett's test of sphericity was significant at $P < .001$, the sample size was adequate to run EFA.[27]

The PCFA extracted four factors [Table 4] after following all necessary steps to remove the cross and poor loading factors. Domains that could not discriminate groups of NDD from each other were also deleted (Table not shown). Component matrix scores of 0.5 or above only were considered in the rotation matrix to identify high loading factors, as the sample size is less than 150.[27] Some of the domains, like vocabulary, could not be identified under any factor because of a low factor loading score. A total of 16 subtests yielded a 4-factor solution. The analysis revealed that a total of seven subtests were loaded on the first factor, three on the second factor, four on the third factor, and the remaining two on factor 4. This resulted in the best-defined factor structure with only two domains, SM and pragmatics (PRG) task the factor loading was below 0.60.

A descriptive level was given to each factor based on the resemblance in the subtests. It can be seen in Table 4 that the first factor is loaded with five subtests requiring scholastic abilities, one subtest of visual reasoning (VR), and one subtest of Fine-Motor Skill. This factor was renamed as scholastic-cognitive-motor skill. The second factor is loaded with three subtests requiring auditory-VUAT and sequential processing.

Table 3: Age- and gender-wise distribution of NC and NDD

Group (Years)	4.5–5.5	5.5–6.5	6.5–7.5	7.5–8.5	8.5–9.5	Total
NC	21 (23%) M=10, F=11	20 (22%) M=9, F=11	20 (22%) M=10, F=10	20 (22%) M=10, F=10	10 (11%) M=7, F=3	91 (M=46 [50.5%], F=45 [49.5%])
NDD	15 (26%) M=11, F=4	10 (18%) M=6, F=4	12 (21%) M=10, F=2	15 (26%) M=11, F=4	5 (9%) M=5	57 (M=43 [75.4%], F=14 [24.6%])

NC – Normal children, NDD – Neurodevelopmental disorder, M – Male, F – Female

Table 4: Factor extraction of the subtests

Rotated Component Matrix[a]				
	Component			
	1 (Variance=45.50%)	2 (Variance=9.84%)	3 (Variance=7.42%)	4 (Variance=6.79%)
WR	0.87			
NA	0.86			
COM	0.83			
SPL	0.79			
QT	0.75			
VR	0.63			
SM	0.57			
AUATRR		0.80		
VUATTIM		-0.77		
VSQM		0.69		
ARP			0.81	
ACOM			0.67	
AVL			0.61	
PRG			0.52	
LTR				0.83
VUATRR				0.67

Extraction method: Principal component analysis. Rotation method: Varimax with Kaiser normalization. WR – Word reading, NA – Numerical ability, COM – Comprehension, SPL – Spelling, QT – Quantitative thinking, VR – Visual reasoning, SM – Small muscle, AUATRR – Auditory attention right response, VUATTIM – Visual attention time, VSQM – Visual sequential memory, ARP – Auditory repetition, ACOM – Auditory comprehension, AVL – Auditory verbal learning (all trial), PRG – Pragmatics, LTR – Letter recognition, VUATRR – Visual attention right recognition

This factor was hence renamed as Attention Skill. The Third Factor is loaded with three language tasks and one verbal learning task. Hence, this factor was renamed as Language Skill. The Fourth Factor was loaded with two subtests requiring scanning and recognition of visual letters or objects. This was renamed as Visual-Perceptual Skill.

Other psychometric properties of the tool were also established. For the assessment of reliability, internal consistency within as well as between the factors was calculated through the correlation matrix (Table not given), and it revealed that the domains within the factors were highly correlated. The correlation between the factors was also significant, suggesting that the factors are inter-related and that a deficit in one area may influence the function in other areas too.

For the establishment of Discriminant Validity, NC and NDD children were compared on all four factors [Table 5]. Both the groups differed significantly in all the factors, including subdomains, except in VSQM. Hence, it could be said that the test is able to discriminate NC from the NDD group successfully. A similar assessment was also done across five age groups and between various NDD groups. Part of this assessment is given in Table 6.

Table 5: Discrimination of domain scores in two groups NC and NDD

Group Statistics					
Subtests	**Group**	***N***	**Mean**	**SD**	***t*-score**
Factor 1 (Scholastic–Cognitive–Motor Skill)					
WR	NC	91	28.62	13.75	5.53*
	NDD	57	15.63	14.12	
NA	NC	91	26.59	7.79	3.43*
	NDD	57	22.26	7.10	
COM	NC	91	48.48	38.52	4.24*
	NDD	57	24.39	23.83	
SPL	NC	91	19.36	7.64	5.35*
	NDD	57	12.46	7.64	
QT	NC	91	22.67	6.33	5.95*
	NDD	57	15.40	8.48	
VR	NC	91	6.25	2.60	2.75*
	NDD	57	5.14	2.01	
SM	NC	91	21.04	2.67	2.95*
	NDD	57	19.58	3.34	
Factor 2 (Attention Skill)					
AUATRR	NC	91	26.33	3.15	4.53*
	NDD	57	22.16	7.85	
VUATTIM	NC	91	39.29	12.28	-3.26*
	NDD	57	52.61	35.79	
VSQM	NC	91	16.71	6.47	1.01**
	NDD	57	15.51	7.87	
Factor 3 (Auditory–Verbal Skill)					
ARP	NC	91	14.33	2.48	4.14*
	NDD	57	11.79	4.95	
ACOM	NC	91	13.76	2.95	7.60*
	NDD	57	9.65	3.57	
AVL	NC	91	39.58	9.51	6.61*
	NDD	57	28.05	11.54	
PRG	NC	91	14.93	5.40	11.43*
	NDD	57	5.72	3.54	
Factor 4 (Visual–Perceptual Skill)					
LTR	NC	91	70.96	0.21	6.49*
	NDD	55	69.53	2.09	
VUATRR	NC	91	28.93	1.87	5.43*
	NDD	57	26.09	4.42	

*Significant at $P<0.01$. **Not Significant. NC – Normal children, NDD – Neurodevelopmental disorder, SD – Standard deviation, WR – Word reading, NA – Numerical ability, COM – Comprehension, SPL – Spelling, QT – Quantitative thinking, VR – Visual reasoning, SM – Small muscle, AUATRR – Auditory attention right response, VUATTIM – Visual attention-time, VSQM – Visual sequential memory, ARP – Auditory repetition, ACOM – Auditory comprehension, AVL – Auditory verbal learning (All trials), PRG – Pragmatics, LTR – Letter recognition, VUATRR – Visual attention right recognition

DISCUSSION

Academic underachievement is a difficult and common experience of most children with childhood disorders. The cause and nature of the difficulties are different for every child and every disorder. Because brain dysfunction in childhood has implications on multiple regions of the brain, detecting co-morbidities is a very significant necessity for planning intervention.[28] It is well established that neurodevelopmental dysfunction that reflects disruptions of the neuroanatomic structure may affect psychophysiological function too, making the child at-risk for cognitive, developmental, emotional, behavioral, social, and adaptive challenges including academic functions.[29] Studies have identified core neurodevelopmental processes that are critical for academic success and these include Sensory-Motor, Language, Visual-Perceptual, and Cognitive development.[29] The current study incorporated all these developmental functions in the new tool [Table 1] and also included domains related to academic skills. The conceptualization of the tool was comprehensive from the neurodevelopmental perspective, and its need in the Indian context cannot be denied as there is a lack of a standardized comprehensive assessment tool, especially in the Bengali population.

In this context, it might be helpful to discuss the reasons for the selection of perceptual-motor as well as cognitive tasks to assess children with neurodevelopmental disorders. Motor coordination problems are common in children with ADHD[30] with associated cerebellar dysfunction. Studies have reported a smaller cerebellum size in ADHD children.[31,32] Movement deficits are also evident in SLD,[33] LD[34] and autism,[35] though the assessment and research focus is not primarily on this domain.

Table 6: Comparison between various NDD groups and NC

Subtests	Group	*N*	Mean Rank	Chi-Square Value
Factor-1				
WR	SLD	28	48.93	34.96**
	LD	10	36.60	
	ADHD	10	50.65	
	ASD	9	59.67	
	NC	91	90.62	
NA	SLD		64.16	11.62*
	LD		61.70	
	ADHD		59.80	
	ASD		46.44	
	NC		83.48	
COM	SLD		60.09	14.42**
	LD		49.00	
	ADHD		54.95	
	ASD		65.39	
	NC		84.79	
SPL	SLD		59.89	31.18**
	LD		23.80	
	ADHD		60.25	
	ASD		50.22	
	NC		88.53	
QT	SLD		63.79	32.26**
	LD		23.45	
	ADHD		53.50	
	ASD		45.67	
	NC		88.57	
VR	SLD		62.16	14.02**
	LD		43.20	
	ADHD		54.80	
	ASD		81.39	
	NC		83.22	
SM	SLD		75.38	16.60**
	LD		32.70	
	ADHD		52.25	
	ASD		61.33	
	NC		82.57	
Factor 2				
AUATRR	SLD		64.71	21.61**
	LD		36.20	
	ADHD		42.05	
	ASD		71.11	
	NC		85.62	
VUATTIM	SLD		74.66	7.43
	LD		106.55	
	ADHD		78.15	
	ASD		84.72	
	NC		69.52	
VSQM	SLD		74.59	7.09
	LD		50.30	
	ADHD		59.70	
	ASD		97.00	
	NC		76.53	
Factor 3				
ARP	SLD		71.62	18.69**
	LD		25.60	
	ADHD		75.85	
	ASD		69.06	
	NC		81.15	
ACOM	SLD		40.80	58.54**
	LD		27.15	
	ADHD		52.35	
	ASD		46.06	
	NC		95.32	
AVL	SLD		49.93	38.52**
	LD		21.60	
	ADHD		63.75	
	ASD		61.11	
	NC		90.38	
PRG	SLD		44.66	76.98**
	LD		20.25	
	ADHD		31.60	
	ASD		32.72	
	NC		98.49	
Factor 4				
LTR	SLD		55.75	67.12**
	LD		51.44	
	ADHD		23.80	
	ASD		40.33	
	NC		89.64	
VUATRR	SLD		70.54	24.00**
	LD		38.55	
	ADHD		43.00	
	ASD		55.67	
	NC		84.99	

*Significant at $P<0.05$. **Significant at $P<0.01$. WR – Word reading, SLD – Specific learning disorder, LD – Language disorder, ASD – Autism, ADHD – Attention deficit hyperactive disorder; NC – Normal children, NA – Numerical ability, SPL – Spelling, QT – Quantitative thinking, VR – Visual reasoning, SM – Small muscle, AUATRR – Auditory attention right response, VUATTIM – Visual attention-time, VSQM – Visual sequential memory, ARP – Auditory repetition, ACOM – Auditory comprehension

The initial factor analysis classified the tool into four factors, namely, scholastic–cognitive–motor skill, attention skill, language or auditory–verbal skill and visual–perceptual skill. The division of four-factor goes pretty well with the understanding of the neurodevelopmental process from the information processing perspective.[36-38] The most popularly used NIMHANS Index for the SLD tool has also incorporated similar domains except the Language domain. The emergence of auditory–verbal as a separate factor shows it is important for assessing NDD and in planning intervention.

Verbal reasoning, a task related to the executive function of cognitive development[39] been better understood with tasks related to attentional skill in the second factor. However, most of the scholastic skills, including reading COM, SPL, numerical ability (NA), etc., as reported by some recent researches are highly predicted by executive function tasks,[40,41] especially

reasoning and critical analysis.[42] Other authors have reported that fine motor skill is one of the key factors for academic readiness in children[43,44] and this skill along with executive function skills are the strongest predictors of academic achievement.[45] This might be the reason that VR and SM tasks were identified with Factor 1. However, during the assessment, it might be beneficial to interpret the findings separately for scholastic, cognitive/executive function and fine-motor tasks for a better understanding of the underlying process of the academic deficit.

Factor 2 rightly identified the task related to attentional processes and included tasks on sustained visual attention and sustained auditory attention (AUA). Both of these tasks also assess discrimination and sensory disinhibition. This factor has also identified VSQM that assesses recognition of sequence and reproduction of the same. Though this is part of visual short-term memory, this is also considered as a measure of sequential attention, which is highly related to the reading and SPL ability of an individual.[46]

The third factor identified the tasks on auditory–verbal skills, though it has excluded some of the core tasks related to auditory-verbal skills, such as syntax and phonological awareness. As tasks such as auditory comprehension (ACOM) and repetition involve both syntactic knowledge and phonological awareness skill, they might be considered as multifaceted tasks that engage all aspects of language or auditory-verbal processing.[47] PRG skill is necessary for conversation and social communication. In many neurodevelopmental conditions, including communication disorder, ASD and language impairment, the role of PRG skill deficit is well established.[48] Its implication in other NDD like ADHD is also documented.[49] The Auditory Verbal Learning Task, a primary measure of the verbal learning potential of an individual,[50] was identified in this factor as it involves auditory-verbal processes of learning. Total Learning score was only considered as it is found to be developmentally sensitive.[51]

The fourth factor, renamed as perceptual skill, includes two specific tasks of letter recognition (LTR) and identification of the appropriate visual stimuli. Both the tasks demand visual searching from the crowding of letters or pictorial stimuli. Both tasks involve perceptual learning, which is crucial for proper reading.[52]

Psychometric analysis suggests that the internal consistency of the tool is high. As most of the tasks were developmentally oriented, making two halves of every subdomain consisting of similar tasks was not possible; thus, split-half reliability could not be tested. The establishment of construct validity and discriminant validity are the strengths of this tool. Despite having a smaller sample size, this tool has other advantages; authors have tried their best to keep it culturally appropriate by developing original items. When we conceptualized the tool, it appeared as a lengthy one, but after PCFA, it has become almost half in length, and that would considerably reduce the administration time. Moreover, the mean and SD scores of NC could be used to decide the task-wise deficit of children with NDD.

However, the tool is not out of limitations that may be taken care of during the future expansion of the tool. More samples from normal, as well as clinical populations, might be helpful to minimize the effect of sampling bias. Moreover, the establishment of test-retest reliability and concurrent validity of the tool should be incorporated and that will further strengthen the psychometric property of the battery. There is also a scope to expand the tool to get a specific profile of various NDD subgroups, which might guide us to obtain specific diagnostic indicators.

CONCLUSION

Various NDDs follow similar cognitive processes and have high comorbidity with each other. These often create diagnostic confusion and result in a delay in proper diagnosis. At the same time, there is a lack of appropriate assessment tools for early detection of the difficulty. As a result, early intervention is mostly very difficult in a country like ours. The tool introduced in the paper is an effort to fill this gap and can be used for treatment planning, too. The current study is probably among very few endeavors to develop a test to assess scholastic backwardness across NDD in Bengali-speaking children. This tool has several advantages, including culture specificity, incorporation of most of the theoretical domains, statistical soundness, and applicability for a wide- range of NDDs at the preprimary level.

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Conflicts of interest
There is no conflict of interest.

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Original Article

The Prevalence of Specific Learning Disorder among School-going Children in Ernakulam District, Kerala, India: Ernakulam Learning Disorder (ELD) Study

Deenu Chacko, Karunakaran Vidhukumar

ABSTRACT

Background: Specific learning disorder (SLD) is a neurodevelopmental disorder characterized by impairment in reading, written expression, and mathematics. The government provides several educational and social benefits to students with SLD, hence, an accurate assessment of the prevalence of SLD is important. This study is an attempt to find the prevalence of SLD and its determinants among the school-going children in Ernakulam district, Kerala, India. **Methods:** School-going children from the fourth standard to the seventh standard were included in the study. Multistage stratified cluster sampling was used. The screening for SLD was done using the LD screening tool, and confirmation of the diagnosis was made using the NIMHANS index for SLD and Malin's Intelligence Scale for Indian Children (MISIC). **Results:** The prevalence of SLD was 16.49% (95% CI =14.59-18.37). The prevalence of impairment in reading, written expression, and mathematics was 12.57%, 15.6%, and 9.93%, respectively. Binary logistic regression analysis showed that male gender, low birth weight, presence of developmental delay, family history of poor scholastic performance, and syllabus were independently associated with SLD. **Conclusions:** The study found a higher prevalence of SLD (16.49%) and certain modifiable determinants of SLD were identified. It highlights the need for early detection and remedial measures for children with SLD.

Key words: *Ernakulam, India, prevalence, specific learning disorder*
Key messages: *The prevalence of SLD was found to be 16.49%. Impairment in written expression was the most common type of SLD identified. Some modifiable obstetric determinants of SLD were also identified.*

Specific learning disorder (SLD) is a neurodevelopmental disorder. It includes impairment in reading, written expression, and mathematics.[1] Combined types of SLD occur more frequently than isolated types.[2] The prevalence estimate of SLD varies between 5% and 15%.[1] In a study done in India at the National Institute of Mental Health and Neurosciences (NIMHANS) Bangalore, the total prevalence rate of SLD was 12%.[3]

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In the school population, the prevalence of SLD in written expression was 8–15% and 6% of the school population had mathematical difficulties.[4,5] In a study done in south India, the prevalence of SLD was 15.17%; while 12.5%, 11.2%, and 10.5% had dysgraphia, dyslexia, and dyscalculia, respectively.[6]

Although, some studies have shown that there is no significant gender difference in reading disability, several others have shown that SLD is more frequent in boys.[1,7] The prevalence of SLD was found to be higher in lower classes compared to higher classes.[8] There is a significant risk for the child to develop reading disability if either parent reports difficulty in reading.[9] Low maternal education, very low birth weight, low 5-minute APGAR score, and other obstetric factors are associated with a high risk for learning disability.[10-12] Prevalence studies on SLD using a validated screening tool exclusively for SLD and studies on determinants of SLD are sparse in India, especially in Kerala. Therefore, we aim to study the prevalence and determinants of SLD through our present research.

SUBJECTS AND METHODS

This cross-sectional study was carried out from February 2018 to January 2019, among children studying in the fourth standard to the seventh standard in private (both financially aided by government and unaided by the government) and government schools in Ernakulam district. Children with visual, hearing, or locomotor impairments that interfere with the assessment; children above 12 years of age; children from whose parents a valid consent could not be obtained, as well as children from whom assent could not be obtained were excluded from the study.

The sampling technique adopted was multistage stratified cluster sampling. The proportion of children following different syllabi (central board for secondary education [CBSE and State]) were maintained in the sample selected. The schools were randomly selected from each stratum, and clusters of children were taken from the selected schools. Each cluster consisted of 20–40 children. Based on the prevalence of 10%, a design effect of 1.5, and a nonresponse of 20%, the sample size calculated was 1560. The sample available to find an association between variables was 1437, after excluding intellectual disability and borderline intelligence.

Study procedure: The Ethics Committee's approval for the study was obtained. Children studying in the fourth standard to the seventh standard, who satisfied the inclusion and exclusion criteria, were included in the study after taking permission from the school authorities, consent from the parents, and assent from children. From each of the four educational districts in Ernakulam's revenue district, the schools were selected randomly by taking lots. Then, clusters of children from the fourth standard to the seventh standard were chosen from these selected schools. An awareness program was conducted for the teachers from these selected schools. The teachers distributed the screening proforma, the proforma for the collection of sociodemographic and other variables, and the consent forms to the parents. The filled up proformas were later collected back by the teachers and handed over to the investigator. Those children who scored more than ten in the screening questionnaire were considered positive for SLD. These children were individually evaluated by using NIMHANS Index for SLD and Malin's Intelligence Scale for Indian Children (MISIC) to confirm the diagnosis. In Kerala, the English language is taught in all schools from the first standard. In the cases wherein we had a doubt whether the language problem in the child was due to English language used in NIMHANS Index, we reassessed the child with Malayalam textbook from the same school, and if the child was not able to read or write up to 2 standards below his/her standard, then the child was considered as having SLD. The subtypes of SLD were also identified. Parents of 40 children whose LD score was less than ten were randomly selected and contacted by the principal investigator to check the quality of the data collected. The children diagnosed were referred for further management.

Tools

1. Proforma for the collection of sociodemographic and other variables
2. Learning disorder screening tool: This is a 26-item, self-administered screening tool given to teachers or parents to screen children for SLD. It has a sensitivity of 100%. It was developed and validated in Malayalam, among the school children of Kerala. LD score of more than ten is considered a test positive[13]
3. NIMHANS Index for SLD was developed in the Department of Clinical Psychology, NIMHANS, Bangalore. It consists of tests of reading, writing, spelling, and arithmetic abilities, to identify children with disabilities in these areas. It consists of two levels. A performance of two standards below the child's present standard is considered as a diagnostic feature of SLD.[14] The Rights of Persons with Disabilities (RPWD) act 2016 recommends the NIMHANS index for the diagnosis of SLD
4. MISIC (Malin's Intelligence Scale for Indian Children) is the Indian adaptation of the Wechsler Intelligence Scale for Children (WISC).[15] It has 11 subsets, classified into verbal and performance

subsets. The test-reset reliability is 0.91; concurrent as well as congruent validity has also been established. This tool has been widely used in the Indian context for assessing intellectual abilities in children. We used it to identify children with intellectual disabilities and borderline intelligence.

Analysis plan and Statistical methods

The statistical analysis was done by R statistical software. The data were summarized, as means and proportions with their 95% confidence interval (CI) for continuous and categorical variables, respectively. The Chi-square test was used to test associations and the odds ratio was used to express the strengths of associations. Binary logistic regression was used for adjusted analysis.

RESULTS

The total number of filled-up screening proformas collected was 1548. We had to exclude 68 proformas due to poor quality and as we could not get some children for individual assessment. The final sample available for analysis was 1480; among them, 429 children screened positive for SLD. The children screened negative were considered as not having SLD.

The sample contained children of the age group 8–12 years. There was almost an equal representation of students from each standard. The majority (61.82%) of the sample were from middle and high-income groups. Most children were from the panchayat or municipality area and 71.22% were following state syllabus. The prevalence of SLD was estimated to be 16.49% (95% CI = 14.59-18.37) [Table 1].

The prevalence of impairment in reading, written expression, and mathematics was found to be 12.57%, 15.6%, and 9.93%, respectively. The prevalence of mixed type (reading/writing impairment along with mathematics impairment) was 9.26%. Among those with SLD (n = 244), 75% had a combination of impairment in reading and written expression, 54.92% had a combination of impairment in written expression and mathematics, 44.67% had a combination of reading, written expression, and mathematical impairment, 9.43% had impairment in written expression only, and 4.1% had impairment in mathematics only.

An analysis of the association of various parameters with the diagnosis of SLD showed that SLD was more common among boys (Odds Ratio [OR] = 2.02, CI = 1.50-2.73, $P < 0.001$) and in children from low socioeconomic status (OR = 1.96, CI = 1.49-2.59, $P < 0.001$). State syllabus (OR = 6.97, CI = 4.17-11.57, $P < 0.001$,) place of residence ($P = 0.005$), high maternal education (OR = 0.237, CI = 0.156–0.359, $P < 0.001$), high paternal education (OR = 0.325, CI = 0.23–0.447, $P < 0.001$), mode of delivery ($P = 0.009$), low-birth-weight (OR = 2.69, CI = 1.93–3.75, $P < 0.001$), preterm birth (OR = 2.8, CI = 1.63–5.05, $P < 0.001$), presence of developmental delay (OR = 6.75, CI = 3.98-11.50, $P < 0.001$), presence of physical illness (OR = 4.8, CI = 2.35-9.88, $P < 0.001$), and family history of poor scholastic performance (OR = 14.4, CI = 9.59-21.60, $P < 0.001$)

Table 1: Proportion of sociodemographic variables and diagnosis

Variables	Group	Frequency	Percentage of the total sample	95% CI
Standard	4	349	23.58	
	5	372	25.14	
	6	379	25.61	
	7	380	25.68	
Gender	Male	752	50.81	
	Female	728	49.19	
Socioeconomic status	High and middle	915	61.82	
	Low	565	38.18	
Religion	Hindu	721	48.72	
	Christian	484	32.7	
	Muslim	275	18.58	
Place of stay	Panchayath	594	40.14	
	Municipality	597	40.34	
	Corporation	289	19.53	
Syllabus	Kerala state	1054	71.22	
	CBSE	426	28.78	
Diagnosis	Nil	1193	80.61	
	SLD	244	16.49	14.59-18.37
	Borderline intelligence	33	2.23	1.47-2.98
	Mental retardation	10	0.68	0.25-1.09

CBSE – Central Board for Secondary Education, SLD – Specific learning disorder

were the other variables significantly associated with SLD in bivariate analysis. There was no significant association between age of the child, religion, standard in which the child is studying, maternal or paternal age at childbirth (32 years was taken as median cut off for paternal age, and 26 years was taken as median cut off for maternal age). or birth order of the child, and the diagnosis of SLD [Tables 2 and 3].

Binary logistic regression analysis for various parameters showed that male gender, low-birth weight, presence of developmental delay, family history of poor scholastic performance, and studying in state syllabus schools were independently associated with SLD [Table 4].

DISCUSSION

In our study, 244 (16.49%) children were having SLD. Previous studies on SLD had shown a variable prevalence of 5%–15%.[1] In a study by Mogasale, the prevalence of SLD in a city in southern India, which is geographically near to Ernakulam district, was found to be 15.17%.[6] However, a study done in NIMHANS Bangalore found the prevalence of SLD to be 12%, and a study done at Varanasi found the prevalence of SLD as 13%.[3,16]

Compared to later studies, our study has a higher prevalence. This may be due to the different diagnostic tools used in the various studies and differences in the populations studied. Another important observation was that, though the prevalence of SLD was higher in the study, none of the children with SLD had been evaluated or identified as having SLD earlier, and none were undergoing any remedial education. This shows the lack of a system for early identification of SLD and a lack of awareness about SLD among teachers and parents.

We did not find any relationship between age or standard in which the child is studying and SLD, unlike previous studies which showed that SLD is more common in the younger age groups.[8] This indicates the lack of early identification and interventions for SLD in the state, especially in lower primary and upper primary classes.

Among children with SLD, the majority (65.16%) were boys. In the bivariate and adjusted analysis, male gender was found to be associated with SLD. This finding is similar to the previous studies done in this area.[2,6,17,18] Some studies have shown that boys are affected more with spelling disorder and girls with arithmetic disorder.[2]

A higher proportion of children from the low-income group had SLD than those from the high- and middle-income groups, and this finding is similar to the previous studies.[10,17] This association may be due to the fact that children in middle- and high-income groups may have better access to early identification and remedial education for SLD and better support from parents. But socioeconomic status was not an independent predictor of SLD as evidenced by logistic

Table 2: Association of sociodemographic variables with SLD

Variables	Group	SLD (*n*=244)	No diagnosis (*n*=1193)	Chi-square (*P*)	Odds Ratio (95%CI)
Gender	Male	159 (65.16%)	573 (48.03%)	23.8 (<0.001*)	2.02 (1.50-2.73)
Socioeconomic status	Low	125 (51.23%)	416 (34.87%)	22.4 (<0.001*)	1.96 (1.49-2.59)
Place of stay	Panchayat	107 (43.85%)	467 (39.14%)	10.34 (0.005*)	
	Municipality	107 (43.85%)	472 (39.56%)		
	Corporation	30 (12.30%)	254 (21.29%)		
Syllabus	State	227 (93.03%)	784 (65.72%)	71.17 (0.001*)	6.97 (4.17-11.57)

*$P<0.05$, CI – Confidence interval, SLD – specific learning disorder

Table 3: Association of other variables with SLD

Variables	Group	SLD (*n*=244)	No diagnosis (*n*=1193)	Chi-square (*P*)	Odds Ratio (95% CI)
Birth weight	<2.5 kg	65 (26.63%)	142 (11.9%)	34.49 (<0.001*)	2.69 (1.93-3.75)
Type of delivery	Normal	114 (46.72%)	681 (57.08%)	9.4 (0.009*)	1.22 (1.06-1.44)
	Instrumental	11 (4.51%)	34 (2.5%)		
	Cesarean	119 (48.77%)	478 (40.06%)		
Birth	Preterm	20 (8.2%)	36 (3.01%)	14.7 (<0.001*)	2.8 (1.63-5.05)
Father's education	Above 10th standard	57 (23.36%)	577 (48.36%)	50.36 (<0.001*)	0.33 (0.23-0.45)
Mother's education	Above 10th standard	27 (11.06%)	411 (34.45%)	51.18 (<0.001*)	0.24 (0.16-0.36)
Developmental delay	Present	33 (13.52%)	27 (2.26%)	61.42 (<0.001*)	6.75 (3.98-11.50)
Family history of scholastic backwardness	Present	84 (34.42%)	42 (3.5%)	238.03 (<0.001*)	14.4 (9.59-21.60)
History of physical illness	Present	15 (6.15%)	16 (1.30%)	19.95 (<0.001*)	4.8 (2.35-9.88)

*$P<0.05$, CI – Confidence interval, SLD – Specific learning disorder

Table 4: Reduced model of Binary Logistic Regression

Variables	Z	OR	95% CI	P
Low birth weight	-4.61	1.79	1.21-2.64	<0.001*
Developmental delay	2.94	2.88	1.56-5.31	<0.001*
Family history of scholastic backwardness	3.38	9.29	6.07-14.20	<0.001*
Male Gender	10.25	1.96	1.42-2.70	<0.001*
State Syllabus	-4.10	4.50	2.66-7.59	<0.001*

*$P<0.05$, OR – Odds ratio; CI – Confidence Interval

regression. In a study, the socioeconomic status of those suffering from developmental dyscalculia was significantly lower than rest of the sample and 42% had first-degree relatives with LD.[19]

The children pursuing state syllabus were more affected by SLD compared to those following the CBSE syllabus. The majority of CBSE schools in the state are in the private sector. These schools follow strict admission criteria, and this could be the reason for the above finding.

SLD was seen in a higher proportion in children staying in panchayat and municipality areas than in those staying in the corporation area where access to early detection and remedial education is easier. Both maternal and paternal education were significantly associated with SLD, and the chances for developing SLD decreased as the educational status of the parents increased. This finding is similar to that of a previous study.[10] Our study showed a definite relationship between SLD and developmental delay, which is similar to the findings of other studies.[20,21] Moreover, SLD was more common in children with preterm birth and a previous study also gave the same finding.[22]

A family history of poor scholastic performance was associated with SLD.[9,21,23] We found no significant association between SLD and birth order or consanguinity among parents, unlike some previous studies.[10,17]

Low-birth weight of the child was associated with SLD. This finding is similar to that of some previous studies.[10,22,24] Our study showed that SLD is more common among children born preterm, as confirmed by a previous study.[17]

Bivariate analysis revealed a significant association between the type of delivery and SLD. On dichotomizing the type of delivery into normal and cesarean, it was found that delivery by cesarean section was significantly associated with SLD, as in a previous study.[17]

Physical illness in childhood was associated with SLD. According to earlier studies, there is an increased prevalence of neurodevelopmental disorders such as SLD with a physical illness like epilepsy.[25,26] Another study had shown that hypothyroidism is associated with poor memory, attention, and visuospatial abilities and learning problems.[27]

We found the impairment in written expression as the most common type of SLD, followed by impairment in reading. This finding is in accordance with some previous studies.[17,28] An Indian study had found that the prevalence of impairment in reading and written expression was 22% each and impairment in mathematics was 16%.[29] In primary school children in India, the prevalence of dyslexia, dysgraphia, and dyscalculia has been reported to be 11.2%, 12.5%, and 10.5%, respectively.[6] In a study conducted on 1,476 children, the prevalence of mathematics disorder was 3.6% and that of reading disorder was 2.2%.[30] In a study on 1,075 children, the prevalence of reading disorder and mathematical disorder was 6% and 3.9%, respectively and 3.4% had both mathematics and reading disability.[31] In studies conducted in different countries, the prevalence rates of subtypes of SLD were found to be different from each other, and it may be due to the differences in diagnostic tools used.

Limitations

Though the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) mentions the severity of SLD, we could not assess the severity of SLD due to the nonavailability of a validated tool for the same. Although neurodevelopmental disorders coexist, we were unable to assess the comorbidities of SLD as we were not able to directly contact the parents. Moreover, we were incapable to assess the type of scholastic problems that existed in the parents, as most of them have had no consultations for their problems.

CONCLUSIONS

From India, there are very few prevalence studies on SLD that are methodologically sound and that have tried to find the determinants of SLD; our study is one among them. The study revealed the prevalence of SLD as 16.49%, and it warrants the need for early detection of SLD and more facilities for remedial education. The government should make the early detection of SLD mandatory in schools. Teachers and parents should be given awareness on SLD. Impairment in written expression was the most common type of SLD. The study also found that male gender, low socioeconomic status, residing in panchayath and municipality areas, state syllabus, preterm birth, birth by cesarean section, developmental delay, low paternal and maternal education, history of poor scholastic performance in the family, and history of physical illness in childhood is associated with SLD. Children born with these risk

factors should be carefully screened for deficits in academic skills from early school days, and remedial measures must be started without delay. These measures help the children to cope up with their deficits and to achieve better academic skills and thus provide better self-esteem and quality of life.

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Conflicts of interest
There are no conflicts of interest.

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Original Article

Parental Perspectives on Quality of Life in Adolescents with Cerebral Palsy

Prabhu Prajakta, Sunila John, Rajashekhar Bellur

ABSTRACT

Background: Quality of life (QoL) is an important outcome variable while evaluating intervention effectiveness during adolescence. Limited studies have addressed the issues that affect the QoL in adolescents with cerebral palsy. The present study explores the parent-reported QoL in adolescents with cerebral palsy. **Materials and Methods:** Using a cross-sectional study design, parental perspectives on QoL were investigated among 35 parents of adolescents with cerebral palsy, aged between 13 and 18 years. Performance on seven domains of QoL across age and gender were explored. **Results:** While the maximum QoL was seen in the domain of social well-being, the least QoL was noted for feelings about functioning. Across age, the early adolescence group (13–15 years) had a poorer quality of life in comparison to the late adolescence group (16–18 years). With respect to the gender, though females had a lower QoL scores, a statistically significant difference was observed only for the domain of general well-being and participation. **Conclusions:** From a parental perspective, the major issues of concern in adolescents with cerebral palsy were feelings about functioning, general well-being and participation, and access to services. This information will be useful when establishing management options or assessment protocols to improve their overall QoL.

Key words: *Adolescents, cerebral palsy, parental perspectives, quality of life*

Key messages:

There are various issues that affect the QoL in adolescents with cerebral palsy. From a parental perspective, the major issues of concern in adolescents are feelings about functioning, general well-being and participation, and access to services.

Cerebral palsy (CP) is one of the most common childhood conditions resulting in functional disability. It has been described as "a group of permanent disorders of the development of movement and posture, causing activity limitation, which is attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain". The motor disorders of CP are often accompanied by disturbances of sensation, perception,

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cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems.[1] Management of children with CP, therefore, involves multidimensional treatment regimens.

QoL assessment is an important dimension that has gained worldwide importance over the last 20 years. It refers to an individual assessment of well-being across multiple domains of life. QoL is defined as the "value that an individual assigns to the duration of life as modified by impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy".[2] These evaluations are useful as outcome measures, at different times, to capture the effects of interventions. The assessment of QoL in CP can be self–reported or parent-reported. The use of parent proxy QoL becomes essential in situations of children or adolescents with severe CP not being able to report their own QoL due to certain limitations such as cognitive immaturity and limited social experience. Recently, Das *et al*.[3] explored the primary caregiver perspectives in 50 Indian parents of children with CP between the age group of 4 to 12 years. Their findings revealed that in Hindi speaking children with CP; age and maternal education affected the QoL as compared to other demographic variables such as type of CP or gender. Arnaud *et al*.[4] through their study conducted in Europe among 818 children between 8 and 12 years of age revealed that parents with higher levels of stress often reported a poor QoL in all domains. The study further suggested that increased severity of the condition is not always associated with lower QoL.

Adolescence is a transition phase to adulthood, characterized by major changes in physical, cognitive, and social aspects. The issues and concerns that affect the QoL of adolescents are very different from those of children and cannot be generalized from findings of QoL in childhood or adulthood. It is highly possible that new impacts on their QoL take place and new domains of QoL emerge in adolescence.[5-7] Waters *et al*.[5] have suggested that adolescents with CP report poorer emotional and social health and that QoL is dependent on pain, mental health issues, general health condition, and how it affects activities at home. A decrease in life satisfaction during adolescence has also been reported in the literature.[6] The primary areas which have a large impact on the QoL of adolescents are their relationship with peers and friendships, self-image and appearance, and the importance of having a secure family and parental relationship.[5,6]

Parental reports provide a perspective on more functional and future-directed information. They also give insight into the associated factors that cause the adolescents' QoL to be poorer, such as access to services, which is not frequently reported by adolescents but is a major contributor to their overall QoL. Rapp *et al*.[8] based on a longitudinal study among 551 adolescents with CP between 13 and 17 years of age, suggested that pain, psychological problems, and parental stress are suggestive of lower QoL as compared to the severity or sociodemographic variables. Another study has suggested that environmental barriers at home and school influence the QoL of adolescents with CP.[9] Most of the parents often feel dissatisfied with the service delivery of medical facilities.[10] The responsibility of caring for an adolescent with CP affects the parents' physical and social well-being, freedom, family well-being, and financial stability. However, in the Indian context, there are no published studies focusing on understanding parental perspectives on their adolescents' QoL. This necessitates the need to evaluate proxy reported QoL among children and adolescents with CP. Therefore, this study aimed to examine the parental perception of the QoL of adolescents with CP. The objectives of the study were to report the parents' perception of their adolescent's QoL by extracting domain-specific effects on QoL and to compare the parental perception of QoL in adolescents with CP across age groups and gender.

MATERIALS AND METHODS

A cross-sectional study design was opted for, and 35 parents of adolescents with CP were included in the study. Ethical approval was obtained from the Institutional Research Committee. The data was collected from both the parents of adolescents with CP coming to the rehabilitation unit of a tertiary hospital in Karnataka. As per the participant selection criteria, using convenience sampling, only parents of adolescents aged between 13 and 18 years and with any type of CP, with Kannada as their mother tongue, and belonging to any socioeconomic background were considered for the study. However, parents with a low level of education or schooling of fewer than 4 years and having adolescents with multiple disabilities were excluded from the study.

The parent-reported QoL was assessed using the Cerebral Palsy Quality of Life Questionnaire – Teen v2.0 (CPQOL – Teen), parent proxy version (for adolescents aged between 13 and 18 years)[11] after obtaining the permission from the authors. This tool is a condition-specific questionnaire to measure the QoL in adolescents with CP. It comprises 88 items that include questions about family and friends, school, participation, communication, health, special equipment, pain and bother, access to services, and a few questions about themselves (parents). The questions are categorized into seven domains: general well-being

and acceptance, communication and physical health, school well-being, social well-being, access to services, family health, and feelings about functioning. The tool, originally developed in English, was translated into Kannada language using a forward-backward translation procedure by four native speakers of Kannada.

Informed consent was sought for administering the questionnaire, from the parents of the children, prior to the study. Demographic details, encompassing adolescent's age, gender, the severity of impairment using gross motor functioning classification system,[12] type of CP, parental level of education, occupation, and socioeconomic status using Kuppuswamy's socioeconomic scale: Revised Income for 2014,[13] were obtained from the parents.

Parents were informed that questions asked to him/her are regarding their adolescent's life, such as his/her family, friends, health, and school. Each question begins with, "how do you think your teenager FEELS about." A visual analog scale of 9 points was presented to the parent to get the response, in which: 1 = very unhappy and 9 = very happy. They were asked to circle the option whichever they feel for each of the items. The responses of each participant were numerically coded for further analysis. Each of the questionnaires was also numerically coded to maintain confidentiality.

Descriptive statistics was used to summarize the performance of seven domains of QoL across age and gender. The mean values of each domain were utilized to compare the domains, and the domain with high scores was identified. An independent *t*-test was performed to find if there is any significant difference across gender and age groups. Statistical analysis was carried out using SPSS version 15, with a confidence interval of 95%.

RESULTS

A total of 35 adolescents (24 males and 11 females) between 13 and 18 years of age were included in the study, as indicated in Table 1. They were divided into two groups, 13–15 years (early adolescence) and 16–18 years (late adolescence). Twenty-four participants (68.6%) were included in the early adolescence group and 11 (31.4%) in the late adolescence group. The early adolescence group comprised of 15 males (62.5%) and 9 (37.5%) females. The mean (SD) age of the group was 13.95 (0.69) years. The late adolescence group included 9 males (81.81%) and 2 females (18.18%). The mean (SD) age of the late adolescence group was 16.36 (1.12) years. The overall mean (SD) age of the participants was 14.82 (1.50) years. The mean age of male and female participants was 14.79 (1.44) and 14.90 (1.70) years, respectively.

Table 1: Demographic characteristics of study participants (*n*=35)

	Age	
	Early adolescence *n*=24 *n* (%)	**Late adolescence *n*=11 *n* (%)**
Gender		
Male	15 (62.5%)	9 (81.81%)
Female	9 (37.5%)	2 (18.18%)
GMFCS		
Level I	0 (0)	0 (0)
Level II	5 (20.83)	4 (36.36)
Level III	9 (37.5)	4 (36.36)
Level IV	8 (33.33)	3 (27.27)
Level V	2 (8.33)	0
Socioeconomic Status		
Class 1	3 (12.5)	2 (18.18)
Class 2	4 (16.66)	2 (18.18)
Class 3	1 (4.16)	3 (27.27)
Class 4	16 (66.66)	4 (36.36)
Class 5	0 (0)	0 (0)

GMFCS – Gross Motor Functioning Classification System

Domain-specific overall performance

The study explored the parental perception of their adolescent's QoL across seven domains. As indicated in Table 2, across the domains, the mean scores were noted to be the highest for social well-being (71.38 [15.21]), with the lowest score on the domain of feelings about functioning (48.50 [24.75]). There was a statistically significant difference between the early adolescence group and the late adolescence group across all the domains except on social well-being.

Across gender, as indicated in Table 3, there was a statistically significant difference between males (60.06 [17]) and females (46.96 [15.44]) only for the domain of general well-being and participation.

DISCUSSION

In the present study, maximum QoL was seen in the social well-being domain while the least QoL was found to be in the domain of feelings about functioning. It was noted that regardless of the motor deficits and communication difficulties exhibited by these adolescents, their parents reported a better QoL related to social aspects. This better score in social well-being can be attributed to the family relationship and public outlook in the Indian scenario. Most often, the adolescents live with their family and are surrounded by family members, resulting in close family bonding. Earlier studies[14,15] have reported that maintaining good relationships with family and friends is crucial for higher QoL. Adolescents need to feel that their CP does not prevent them from being accepted and valued by their families. Similarly, the public outlook towards specially-abled children is fast improving.[16] The masses

Table 2: Domain-specific overall performance and performance across early and late adolescence groups

Domains	Early adolescence mean (SD)	Late adolescence mean (SD)	Overall mean (SD)	*t* statistic, *p* value
General Well-being and Participation	48.58 (13.90)	72.02 (13.19)	55.95 (17.43)	t (33)=-4.7, p<0.01
Communication and Physical Health	51.79 (12.76)	76.70 (13.04)	59.62 (17.26)	t (33)=-5.32, p<0.01
Social Well-being	68.94 (15.13)	76.68 (14.66)	71.38 (15.21)	t (33) =-1.41, p>0.01
School Well-being	58.45 (14.80)	78.03 (12.52)	64.60 (16.72)	t (33)=-0.38, p<0.01
Access to Services	49.46 (13.28)	72.47 (13.78)	56.69 (17.11)	t (33)=-4.70, p<0.01
Family Health	49.09 (21.23)	77.27 (14.66)	57.95 (23.32)	t (33)=-3.97, p<0.01
Feelings about Functioning	38.33 (22.03)	70.68 (13.32)	48.50 (24.75)	t (33)=-4.48, p<0.01

Table 3: Domain wise performance across gender

Domains	Male mean (SD)	Female mean (SD)	*t* statistic, *p* value
General Well-being and Participation	60.06 (17.00)	46.96 (15.44)	t (33)=2.17, p=0.037
Communication and Physical Health	62.63 (17.97)	53.05 (14.16)	t (33)=1.55, p=0.129
Social Well-being	73.26 (15.04)	67.27 (15.49)	t (33)=1.08, p=0.28
School Well-being	66.33 (18.09)	60.83 (13.23)	t (33)=0.90, p=0.37
Access to Services	59.88 (17.77)	49.74 (13.84)	t (33)=1.66, p=0.10
Family Health	62.23 (22.22)	48.60 (23.94)	t (33)=1.64, p=0.10
Feelings about Functioning	51.35 (23.87)	42.27 (26.65)	t (33)=1.00, p=0 0.32

now recognize the needs of the specially-abled and extend their support to them amicably. In the present study also, most of the parents reported that the adolescents were well involved in the family and home environment and got along well with their brothers and sisters. Thus, a feeling of belonging was seen among the study participants.

In the present study, apart from social well-being, the domain of school well-being showed relatively better QoL in comparison to other domains. Supporting evidence from Davis *et al*.[17] parent-reported study indicates that adolescents enjoy school, it being an active and enriching environment helping them to feel being a part of the community. Our finding can also be attributed to the fact that all participants were going to a regular school and enjoyed good peer relationships. Taking this into account, the parents reporting a better QoL for adolescents with respect to the school well-being domain is justified.

In comparison to social and school well-being, poorer QoL was reported for the communication domain. On similar lines, Davis *et al*.[17] reported that parents of adolescents with limited communication reported the frustration they and their children often felt. Similar findings obtained from the current study can be related to the difficulty that parents face in comprehending the adolescent's needs and requirements.

The study findings also revealed a poor QoL with respect to parent-reported physical health. Brehaut *et al*.[18] reported that caregivers tend to be more depressed if their child has poorer health and, in turn, report a poor QoL for their adolescent. Correlation between maternal depression and parent-proxy reported health has also been reported in the literature.[19,20] This, along with increased familial tension and pressure, could be one of the contributing factors for the poor QoL reported in the present study.

The present study findings showed a poor QoL in the domain of family health. According to Davis *et al*.,[17] financial support is essential for childcare and rehabilitation. The financial stability to meet the child's needs had a major impact on QoL related to family health. Along with the above-mentioned factors, Magill-Evans *et al*.[21] reported that if the relationship of the adolescent with his/her sibling was poor, the parents reported the QoL as lower. This may be one of the factors contributing to the poor QoL observed in the present study.

In the current study, 57.14% of the parents were from a poor socioeconomic class. A poor financial condition in the family increases the level of parental stress, which could have affected the parent-report of QoL negatively. Further, a lower QoL score was observed for the domain of availability of services required for the adolescent and their access to these services. This could be explained by the fact that a lack of access to services added extra pressure on the parents while taking care of their adolescents. Darrah *et al*.[22] reported that families experience dissatisfaction and frustration with service delivery in the areas of health, education, work, recreation, housing, and transportation. In the Indian scenario, in rural areas, there is evident difficulty in accessing the required interventional and rehabilitative services. People with disabilities encounter a range of barriers when they attempt to access healthcare.

These include unaffordable costs, limited availability of therapy services, and lack of support groups. In the Indian context, the high cost involved for the services and lack of services was reported to be a common barrier that hinders rehabilitation.[23] This would have also contributed to the lower parent-reported QoL in the current study.

In the present study, poor QoL for the domain of general well-being and participation can be attributed to various factors, including parents' physical and mental health, personality, coping, optimism, and self-esteem. An additional factor that could lead the parents to report a poor QoL in this domain may be their tendency to infer negative conclusions just purely based on the physical, observable behaviors. Previous authors had suggested that parents report more impairment with reference to general well-being.[24,25] The reason for this could be that during adolescence, children do not tend to share their feelings and emotions with their parents quite often. Hence, parents have little access to emotions and feelings their adolescent has when the transition from childhood to adolescence happens. A restriction in the physical mobility of an adolescent renders them inefficient to carry out their daily activities, with increased dependency on others. The parents of adolescents with CP in this study were often burdened with the added responsibility of helping the adolescent carry out self-care activities and other daily needs such as toileting and dressing up. Apart from this, the parents also had the additional responsibility of taking care of household matters and other children in the family. This could be a possible explanation for the findings in our study.

On comparison of performance on QoL across early and late adolescence groups, it was consistently seen that parents of early adolescents reported a poorer QoL in domains encompassing the adolescent's general well-being, communication abilities, academic and schooling related activities, social participation, and familial involvement and support. These are contrary to the findings of Giannakopoulos *et al*.,[26] who reported that late adolescents have poorer QoL than younger adolescents. However, the current study findings are supported by Shikako-Thomas *et al*.,[14] who explained it as an adaptation that occurs in the family of the adolescent with CP because it is a congenital disorder. Parents develop a series of adaptive strategies and adapt their plans and expectations. As adolescents grow older, they learn to cope with the disorder and are much less dependent on the parents for their daily functioning. This might be one of the potential reasons why parents reported a better QoL for the late adolescence group.

On comparison of performance on QoL domains across genders, a strong relationship between the genders and QoL was observed. Without any domain as an exception, parents of female adolescents reported poor QoL in comparison to the males. Among all domains of life, female adolescents seem to have the poorest QoL with respect to mobility and independent functioning. In the Indian scenario, the reason for a poor parental report of QoL among female adolescents with CP may be that as a whole, especially in rural India, females have a lower social status in the community and are considered as an added responsibility.[27] In addition to this, the presence of a lifelong disorder like CP restricts the ability to carry out daily functions, heightens the caregiver's stress towards future planning and worsens the general perception of the community.

CONCLUSION

Overall, the present study outlines the parental perspectives on QoL in adolescents with CP in the Indian scenario. It also provides information regarding QoL from a functional perspective. However, parent-reported QoL could not be used as a substitute for self-reported QoL, as it provides only complementary information about an overall view of the adolescent's QoL. One of the major limitations of the study is the lack of validation of the developed tool. Further, stress levels and overall mental health of the parents and adolescents were not measured. Owing to the limited sample size, a detailed analysis could not be done to evaluate the domain-specific effects of the gross motor function classification system level and socioeconomic status. Future research focussing on the comparison between self-report (after assessing their intellectual capacity) and parent-report of QoL on larger sample size, including different types of CP, is warranted. In addition, studies can be conducted in the Indian context to identify the effects of parental stress and mental health on parent-reported QoL in adolescents with CP and to analyze the psychometric properties (reliability and validity) of the Kannada version of the questionnaire.

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Conflicts of interest
There are no conflicts of interest.

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Original Article

Clinical Profile of Tic Disorders in Children and Adolescents from a Tertiary Care Center in India

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ABSTRACT

Background: Tic disorders (TDs) are common neurodevelopmental disorders in children and adolescents. To date, there is very scant literature on TDs in children and adolescents in the Indian setting. **Aim:** The objectives of this study were to characterize the clinical profile, including comorbidities and pattern of medication use in the treatment of TDs, in children and adolescents. **Materials and Methods:** The present study is a retrospective chart review of children and adolescents up to age 18 years diagnosed with TD in a tertiary care center in India. Data were derived from case records of patients with a diagnosis of TD, coded as F 95 according to ICD 10, from 1st January 2014 to 31st December 2017. **Results:** We recruited 85 subjects. The majority (95.29%, $n = 81$) of them were male, and the mean age of onset was 8.4 years. Chronic tic disorder was the most common subtype, followed by Tourette syndrome and provisional or transient tic disorder. Eighty patients (94%) had a comorbid disorder, with attention deficit hyperactivity disorder being the most common, followed by obsessive compulsive disorder. Eighty-two percent of patients received pharmacotherapy. Risperidone was the most frequently used medication, followed by clonidine, haloperidol, and aripiprazole. Moderate to significant improvement with medications was seen in 88% of the patients. **Conclusion:** The present study of children and adolescents with TDs highlights very high rate of comorbidity and a favorable short-term course with medication use.

Key words: *Adolescent, child, comorbidity, India, tic disorders*

Key message:

- *Ninety-four percent of children with tic disorders had comorbidities.*
- *Risperidone was the most frequently used medication, followed by clonidine, haloperidol, and aripiprazole.*
- *Favorable short-term outcome is seen with medication use.*

Tic disorders (TDs) are one of the neurodevelopmental disorders seen in children in every part of the world. For many, the experience of tics may only be transient — but for those with Tourette syndrome (TS), it may be a debilitating mental health problem.

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As with other neurodevelopmental disorders, boys are more commonly affected than girls with tics. Tic symptoms typically have an onset around the age of 5–7 years and reach their peak severity around 10–12 years of age.[1] In the majority, symptoms subside during adolescence.[2] According to DSM-5 and ICD-10, primary tic disorders include TS (= combined phonic and motor tic disorder), persistent (or chronic) motor tic disorder (CMTD), persistent (or chronic) phonic tic disorder (CPTD), and provisional (or transient) tic disorder (PTD). Primary tic disorders are much more common than secondary tic disorders,[3] which are caused by other conditions, such as certain neurodegenerative disorders, stroke, or substances.[4]

The prevalence rate of TS in children in the general population ranges from 0.3 to 0.9%,[5] whereas the prevalence rate of CMTD ranges from 0.5 to 1.65%.[6] Due to the additional criterion regarding the added presence of phonic tics, TS in the community is rarer in comparison to CMTD.[7] Accordingly, the prevalence for PTD – the mildest form of all primary TDs – is much higher, ranging from 5 up to 47%.[8] In a population-based study[9] from India, the prevalence rate was estimated at 35.34 (95% confidence interval, CI 12.96–76.92) per 100,000 [males: 56.19, 95% CI 18.21–131.15; females: 12.37, 95% CI 0.37–68.93].

TDs are associated with multiple comorbid conditions, which include obsessive compulsive symptoms, attention deficit hyperactivity disorder (ADHD), conduct disorder, oppositional disorder, rage attacks, anxiety, depression, and sleep disturbances.[10] Tics typically have a waxing and waning course, but the long-term outcome is generally favorable. Many pharmacological and behavioral interventions are available. An effective nonpharmacological approach in the management of tic disorders is the habit reversal therapy (HRT).[11]

Medications should be considered for CTD patients with moderate to severe tics that cause severe impairment in quality of life. When medication-responsive psychiatric comorbidities are present, medications that target both tic symptoms and comorbid conditions should be considered.[12] According to the European Child and Adolescent Psychiatry guideline 2011,[13] haloperidol, pimozide, risperidone, and alpha-2 agonists such as clonidine and guanfacine have level of evidence A for use in tic disorders. Haloperidol and pimozide are the only two FDA-approved treatments for tics, although they are not currently recommended as first-line pharmacotherapy because of their adverse side-effect profile.[14]

Limited data are available regarding TDs in children and adolescents in the Indian settings, including a retrospective review of 30 children and a comparison study of obsessive compulsive disorder (OCD) with tics vs. OCD.[15,16] A recent study[17] found that the rate of "any" TD was low (9.9%). However, to date, to the best of our knowledge, there is no literature available exclusively on the clinical profile and medication use in children and adolescents with TDs. Therefore, we report the sociodemographic and clinical profile of children and adolescents with TDs who received treatment at the child and adolescent psychiatry Services of National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru between the years 1st January 2014 to 31st December 2017 (four years duration).

MATERIALS AND METHODS

The present study utilized a retrospective chart review design. Ethical approval was obtained from the Institutional Ethical Committee. Data were derived from case records of patients with a diagnosis of tic disorder, coded as F 95 according to ICD 10 The study site is a tertiary care center in India.

The department offers outpatient and inpatient services to children and adolescents up to age 18. There is no definite catchment area for these services, although a majority of the patients hail from the state of Karnataka and the neighboring states. All patients undergo a detailed clinical evaluation in accordance with a prespecified topical format based on an unstructured psychiatric interview with both the child and the parent(s). The topical format includes sociodemographic information, presenting complaints, a history of present illness in chronological order of complaints, developmental history, temperament, family history, treatment details, and a mental status examination. Diagnosis and management plan are confirmed either by a consultant or a senior resident.

Limited information was available about the clinical status of the subjects at follow-up on standard outcome measures like Yale Global Tics Severity Scale (YGTSS) or Clinical Global Impression (CGI). Hence, the response was categorized into three parts based on the researcher's clinical judgment such as:

- Less than 30 percent improvement - not improved
- 30–60% improvement - moderately improved, and
- More than 60% improvement - significantly improved.

A total of 85 case records with a diagnosis of TD as per ICD 10 were reviewed. Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 21.0 for Windows using descriptive statistics

RESULTS

A total of 12,662 patients attended the out-patient services during this four-year period. We identified 85 patients with a diagnosis of TDs according to the ICD-10 codes (F95-95.9) in the records. Based on the above data, the four-year period prevalence of TDs in the child and adolescent psychiatry outpatient population was 0.67%.

The mean age of presentation was 11.4 (SD: 0.70) years, and 95.2% (n = 81) were boys. Majority of the subjects presented with tics either at school-going age (49.4%, n = 42) or during the adolescent period (48.2%, n = 41). All of the subjects were going to school and 74.11% (n = 63) of them were from an urban locality.

Clinical profile of the patients is summarized in Table 1. The, majority (77.6%, n = 66) had an onset of tics between 6 and 12 years of age (school-going), with a mean age of onset of 8.4 (SD: 2.5) years. The youngest age of onset of tics was four years presented at seven years of age with chronic motor tic disorder (head jerks, eye blinking) and ADHD with a family history of tic disorder. The majority of patients (64.7%, n = 55) had a duration of tics between 1 and 5 years. Psychosocial stressor in the form of bullying was seen in 20% (n = 17) of the sample.

A vast majority (94.1%, n = 80) of the sample had a comorbid condition [Table 2]. The most common comorbid conditions were ADHD (33.75%, n = 27), followed by OCD (21.25%, n = 17) and specific learning disorder (SLD) (13.75%, n = 11).

The pattern of medication use is summarized in Table 3. The majority (82.35%, n = 70) were on both medications and nonpharmacological interventions, resulting in combined treatment. The remaining 17.65 (n = 15) exclusively received nonpharmacological intervention in the form of psychoeducation and HRT.

The response to medications is summarized in Table 4. Documentation of follow-up and response to medication use was available in 45 case records. The mean duration of follow-up was 9.78 months with one patient having a follow-up of maximum of 34 months. Thirty-three patients out of 37 who were prescribed risperidone had documentation regarding follow-up and response.

A total of 10 out of 16 patients who were prescribed clonidine and six out of eight who received haloperidol had follow-up and response records. The response of the child (n = 1) who was on polypharmacy was "not improved". Mean dose (dose range) was 51.56 mcg/d (25–100 mcg/d) for clonidine, 0.72 mg (0.25–3 mg/d) for risperidone, 0.62 mg/d (0.5–1.5 mg/d) for haloperidol, 8 mg/d (5–15 mg/d)

Table 1: Clinical profile of patients (n=85)

Characteristics	Frequency (n)	Percentage	Mean±SD
Age of onset (years)			
Preschool (<5 years)	8	9.41	8.4±2.50
School-going (6-12 years)	66	77.64	
Adolescence (12-18 years)	11	12.94	
Duration of tics (in years)			
<1 year	14	16.47	
1-5 years	55	64.70	36.09±25.60
>5 years	16	18.82	
Characteristics	**Frequency (n)**	**Percentage**	
Type of tic disorders			
Provisional or transient tic disorder	14	16.47	
Chronic tic disorder	43	50.58	
Tourette syndrome	28	32.94	
Family history of tic disorder	3	3.52	

Table 2: Pattern of comorbidity in patients with tic disorders (n=80)

Comorbid disorders (n=80)	Frequency (n)	Percentage
Attention deficit hyperactivity disorders (ADHD)	27	33.75
Obsessive compulsive disorders	17	21.25
Specific learning disorders	11	13.75
Intellectual disability	6	7.5
Oppositional defiant disorder (ODD)	5	6.25
Conduct disorder (CD)	4	5
Generalized anxiety disorders (GAD)	3	2.5
Social anxiety disorder (SAD)	1	1.25
Autism spectrum disorder (ASD)	2	2.5
Psychosis	2	2.5
Dysthymia	1	1.25
Trichotillomania	1	1.25
Expressive speech delay	1	1.25
More than one comorbidity (n=11)		
CTD+ADHD+ODD	3	3.75
CTD+ADHD+CD	3	3.75
TS+ADHD+SAD	1	1.25
CTD+OCD+GAD	1	1.25
CTD+OCD+CD	1	1.25
TS+ADHD+OCD	1	1.25
CTD+ADHD+OCD	1	1.25

Table 3: Pattern of medication use and response to medications (n=70)

Medications (n=70)	Frequency (n)	Percentage
Antipsychotics (n=50) Risperidone	37	52.85
Haloperidol	8	11.45
Aripiprazole	5	7.14
Alpha-2 agonist (n=16) Clonidine	16	22.85
Others: Tetrabenazine	3	4.28

Only one child (1.42%) received polypharmacy in the form of risperidone, clonidine and tetrabenazine

Table 4: Response to medications (*n*=45)

	Frequency (*n*)	Percentage
Response		
Not improved (<30%)	5	11.11
Moderately improved (30-60%)	28	62.22
Significantly improved (>60%)	12	26.66
Risperidone (*n*=23)		
Not improved (<30%)	4	17.39
Moderately improved (30-60%)	14	60.86
Significantly improved (>60%)	5	21.73
Clonidine (*n*=10)		
Not improved (<30%)	-	-
Moderately improved (30-60%)	8	80
Significantly improved (>60%)	2	20
Haloperidol (*n*=6)		
Not improved (<30%)	1	20
Moderately improved (30-60%)	3	60
Significantly improved (>60%)	2	40
Aripiprazole (*n*=5)		
Not improved (<30%)	-	-
Moderately improved (30-60%)	3	60
Significantly improved (>60%)	2	40
Tetrabenazine (*n*=1)		
Not improved (<30%)	-	-
Moderately improved (30-60%)	-	-
Significantly improved (>60%)	1	33.3

for aripiprazole, and 41.6 mg/d (25–75 mg/d) for tetrabenazine. No substantial side effects were noted with any of these medications.

DISCUSSION

The prevalence of TDs in our study was 0.67%, whereas other studies, which are epidemiological and community- based studies, reported prevalence of tics (chronic or transient) ranging from 5.9% to 18% for boys and from 2.9% to 11% for girls[18] and of CTD as 0.5% to 3%.[5] A population-based Indian study[19] reported a crude prevalence of 25 (95% CI 15–34) per 100,000, which is lower than that reported from western countries.

Sociodemographic profile

The mean age at presentation was 11.4 years (SD: 0.70 years), and the mean age of onset was 8.4 years (SD: 2.40 years). Other studies have shown a similar age of onset in tic disorders.[1,20] There may be a delay in the age at presentation due to lack of awareness, mild and transient nature of tic not causing impairment of functioning, or the tics not being noticeable to others.[21]

The sample was overrepresented by boys (95.2%, *n* = 81). This finding is similar to that of an earlier study from our center.[15] Also, in epidemiological studies, the reported male–female ratio varies considerably from 1:1 to 10:1.[22]

Symptom profile

The majority of patients had a duration of tics of more than one year, with a mean duration of 36.09 (SD: 25.60 months) months, indicating chronic nature of the illness.

Previous findings from our center[15] and a meta-analysis reported PTD to be more common compared to CTD. However, in our study, the commonest type of TD was CTD, followed by TS and PTD. This difference in findings could be due to the small sample size in the past study from our centre. In addition, reports of PTD being more common than CTD came from a community-based sample.[23] Another reason for this difference could be an underestimation of PTD prevalence, given that most cases of tics are mild and may be misdiagnosed or unrecognized by medical professionals and may not be impairing to the child or adolescent.

Comorbidity

Comorbidity was found in 94.1% of our sample, which is extremely high and is similar to the finding of a study by Cavanna *et al*.,[24] in which the rate of comorbidities was approximately 90%.

Other studies that included clinical samples of CTD also report that co-occurring psychiatric disorders are common, and patients with CTD meet the criteria for two or more conditions that are often viewed by the patient and family as more problematic than the tics *per se*.[25] Symptoms associated with ADHD and OCD have received the most attention in TDs.[26] Similarly, in our study, the commonest comorbidities were ADHD and OCD. According to a study done by Khalifa *et a*l. in both clinical and epidemiological studies, it is not uncommon to see reports of 30–50% of children with TDs diagnosed with comorbid ADHD which is similar to our finding of 33.75% patients with comorbid ADHD.[27]

Studies have reported 20% to 60% of TD patients meeting criteria for OCD.[28] Some studies reported the prevalence of OCD in TS as high as 40% to 80%.[29,30] However, in our study, the rate of OCD as a comorbidity was found to be only 21.25%. However, the association between OCD and TD appears to be bidirectional,[12] and 20 to 38% of youths with OCD may report comorbid tics.[28] The third commonest comorbidity was SLD, seen in 13.75% (*n* = 11) patients. Other studies too have shown that school-related problems and learning disabilities are common (23%) in youth with chronic tics.[31,32]

It was surprising to see the low rates of mood and other anxiety disorders in our study, which is in contrast to previous studies conducted in the West.[12]

Medication use and response

Treatment for TDs in our study showed that 70 (82.35%) patients were prescribed a combination therapy of medications and psychosocial interventions, and 15 (17.64%) were provided psychoeducation with HRT exclusively. Despite this large number of patients on medications, behavior intervention in the form of HRT and relaxation was provided to all children and adolescents as a part of the treatment of tics. The use of medications was high, probably due to the chronic nature of the TD, comorbidity associated with it, and distress or impairment in functioning in social, academic, and peer relationships independent of the comorbidities. In our sample, 71.42% (n = 50) of patients had received antipsychotics (risperidone being the most commonly used:(52.85%, n = 37), followed by the alpha 2 agonist clonidine (in 22.85%, n = 16), both of which have level A evidence.[13]) Similar to our findings, a clinician survey found that the most common medications used to treat tics are risperidone, followed by clonidine and aripiprazole.[13] About half of the patients (48.14%, n = 13) with TDs and ADHD in our study were on clonidine. Use of clonidine in TDs with comorbid ADHD has been supported by a recent meta-analysis, which found that trials that enrolled subjects with tics and ADHD demonstrated a medium-to-large effect in reducing tic severity (0.68), whereas trials that excluded subjects with ADHD demonstrated only a small, nonsignificant benefit (0.15).[33,34] Tetrabenazine was prescribed in 4.28% (n = 3) of the patients. It is not a frequently used medication in the child and adolescent population. These patients were already on tetrabenazine at the time of referral from the neurology department of our center. One of the positive and encouraging findings was that polypharmacy was noted only in one (1.42%) patient. None of the subjects had a history of Methylphenidate (MPH)- induced tics or antipsychotic-induced serious adverse effects.

The mean duration of follow-up was 9.78 months, which is definitely not sufficient to draw a conclusion about long term outcome or response to medication. However, from the limited duration of follow-ups, we found that with medication use in general, 62.22% of the patients moderately improved, 26.66% had significantly improved, and only 11.11% of the patients had not improved. Response to different classes of medications was no different, wherein subjects who were prescribed risperidone, clonidine, haloperidol, or aripiprazole showed more than 60% response. With these limited findings, we can consider the use of medications in children and adolescents with tic disorders without hesitation.

Strengths and limitations

The obvious drawback of the study is the retrospective design. One-third of the patients did not have even a single follow–up, and outcome-based measures such as YGTSS or CGI were not applied on many.

Out of 70 (82.35%) patients who were prescribed medications, case records of 45 (64.28%) had follow-up visits and response documentation. Twenty-five (35.71%) did not have follow-ups. This could be due to various reasons. Being a tertiary care centre, many patients and family turn up only for a second opinion. Many patients, after two or three sessions of psychoeducation, HRT and relaxation, are referred back to psychiatrists or psychologists in their own cities. Lastly, the natural course of the illness itself may result in irregular follow-ups.

Despite all the drawbacks, it is a comprehensive review of available clinical data on tic disorders in children and adolescents, with a good sample size. Although only a short -term favourable outcome, representing a good initial response to medication, could be documented, it is an encouraging finding

CONCLUSION

Given the high prevalence of comorbidities, particularly ADHD and OCD, they should not be overlooked during the assessment and management of tic disorders. Response to medication in tic disorders seems to be promising in combination with nonpharmacological treatment, at least in the short term.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Prevalence and Profile of Bullying Involvement among Students of Rural Schools of Anand, Gujarat, India

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ABSTRACT

Background: Bullying can have short- and long-term implications on physical as well as mental health. The objective of this study was to assess the prevalence of bullying involvement (bully, victim, and bully–victim) and know profiles of bullying among students of rural schools of Anand, Gujarat, in Western India. **Materials and Methodology:** A questionnaire in the Gujarati language was administered to sixth to tenth graders of 12 rural schools ($n = 2552$) in the Anand district. The questionnaire included four questions each to screen for bullying behavior and victim experiences; Peer Interaction in Primary Schools Questionnaire (PIPSQ, a self-reported measure of individuals' levels of bullying behaviors and victimization experiences), and Strength and Difficulties Questionnaire (SDQ, to assess emotional, behavior, and interpersonal difficulties experienced), apart from demographic information. The analysis of variance (ANOVA)/Chi-square test was applied to determine associations. **Results:** Prevalence of bullying involvement was 70% ($n = 1529$; 9.1% bullies, 18.6% victims, and 42.3% bully–victims). The prevalence of bullies was higher in boys (77.5%) compared with girls (58.3%). In addition, the prevalence of victims was higher in boys (67.2%) compared with girls (51%). No association was found between various categories and family type, birth order, number of friends, or grade. Bully–victim was the worst affected group as per the SDQ profile. **Conclusions:** There is a high prevalence of bullying-related involvement compared with earlier studies and a complete lack of bullying prevention policies at the school level. A simple screening strategy, using a few questions to identify bullying-related involvement, is valid and useful. Guidelines need to be devised to standardize future bullying-related research in India.

Key words: *Bullying, child and adolescent health, India, rural, schools, victimization*

Key messages: *Bullying involvement in the rural population has been unexplored in India. This study highlights the high prevalence of bullying involvement in this population. A simple screening strategy, using a few questions to identify bullying-related involvement, is valid and useful.*

A widely used research definition of bullying is "a child is being bullied or victimized when he or she is exposed, repeatedly and over time, to negative actions on the part of one or more other children."[1] It can also be defined as "intentional, repeated negative (unpleasant and hurtful) behavior by one or more persons directed

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against a person who has difficulty defending himself or herself."[2]

"Bullying involvement" is defined as the combined prevalence of bullies, victims, and bully–victims.[3] Studies in Indian urban schools have reported a 53% prevalence of bullying involvement,[3] 34% prevalence of bullies[3] and 30–60% prevalence of victims.[3-5] A study done in Anand/Vadodara urban schools in 2015, found 49% prevalence of bullying involvement.[6]

In an epidemiological survey on the mental health of schoolgoing adolescents comparing urban and rural populations, it was found that prosocial behavior is significantly higher in rural adolescents.[7] Based on this, we hypothesized that bullying exists in rural schools and that its prevalence might be lesser than in urban schools. To the best of our knowledge, there are no Indian studies on bullying in rural schools. We wished to explore the prevalence and profile of bullying involvement in the rural schools of Anand.

MATERIALS AND METHODOLOGY

A cross-sectional study was conducted in January 2016 at 12 Gujarati-medium schools from the rural areas of Anand district, Gujarat state, in Western India after approval from the institutional ethics committee (IEC). Anand district covers an area of 2941 sq. km and has 365 villages. The rural area was defined as a village/smalltown having a population less than 10,000 (viz. Borsad, Mogri, Anklav, and Gana). Based on the previous study in urban schools of Anand,[6] we assumed a prevalence of 50% of bullying-related involvement. We required a minimum sample of about 400 at a 95% confidence level and 5% acceptable error. However, to enable subgroup analyses and considering feasibility, 12 schools from four villages/small towns were selected randomly that were within a 15-km radius of our institute. Permission was obtained from the school principal before administering surveys. The survey was administered to students from classes six to ten after obtaining the written informed consent of the teacher and assent of the participant. The questionnaire was distributed and recollected from the participants through the teacher. One of the authors briefed the participants about the questionnaire prior to administration.

The survey in Gujarati language included the following:

a. Demographic variables like age, sex, height, weight, scholastic performance, and number of friends
b. Questions to screen and categorize the participants into bullying-related categories
c. Questions to identify bystander behavior and reporting of bullying
d. Peer Interaction in Primary School Questionnaire (PIPSQ)[8]
e. Strengths and Difficulties Questionnaire (SDQ).[9]

To screen and categorize participants into various bullying involvement categories, we followed the method used by Malhi *et al*.[3] Four questions were used to screen participants for bullying behaviors, including:

a. "Have you hit, kicked, pushed, or shoved another student?
b. "Have you called other students names or made fun of them, or teased him or her in a hurtful way?"
c. "Have you spread lies about other students?"
d. "Have you extorted money or things from other students?"

Participants rated themselves on a three-point scale as, "never/rarely," "sometimes" (once or twice in a month), "usually/always" (several times in a month). Students who chose "sometimes" or "usually/always" on any of the above four questions were classified as bullies.

Likewise, four questions were used to screen participants for victim experiences, these were:

a. "Have you been hit, kicked, pushed, or shoved around by another student at school?"
b. "Have you been called names, made fun of, or teased in a hurtful way?"
c. "Have other students told lies or spread false rumors about you and tried to make others dislike you?"
d. "Whether your money or things have been taken away from you or damaged in some ways?"

Participants choosing "sometimes" or "usually/always" on any of the above four questions were classified as victims. Those who met the criteria for bully and victim were classified as bully–victims, and those who did not meet any of the above criteria were classified as noninvolved.

All participants who were classified as victims or bully–victims were asked additional questions related to the place of bullying, the number of children who had bullied them, whether they had reported it, and whether the school or parents had intervened.

The PIPSQ is a self-reported measure of individuals' levels of bullying behaviors and victimization experiences. It is designed for primary school children. After reading the scale items, we observed the face validity to use the questionnaire in our population. There are no other scales available to quantify such behaviors. The PIPSQ consists of 22 questions scored on a three-point scale with answers, "never," "sometimes," and "a lot." It has two subscales, viz. bullying perpetration and victim experiences. For the purpose of this study, the frequency of "never," "sometimes," and "a lot" for each question

was calculated to characterize victim experiences and bullying behaviors for the study population.

The self-reported version (11–17 years) of SDQ was used to assess the emotional, behavioral, and interpersonal difficulties experienced. SDQ has 25 questions, with five subscales, viz. emotional problem, conduct problem, hyperactivity, peer problem, and prosocial behavior. The total difficulties score is calculated by adding the scores of all subscales except prosocial behavior. Responses are scored on a three-point scale—"not true," "somewhat true," or "certainly true." Scores for the subscales were calculated as per the instructions on www.sdqinfo.com. Singh *et al*. have reported acceptable confirmatory factor analysis properties of self-reported SDQ in Indian adolescents.[10]

Translation-back translation methodology was adopted to develop the Gujarati language adaptation of the study questionnaire. Face validity of the adaptation was accepted by the consensus of the study authors (one psychiatrist and three pediatricians). The Gujarati version of SDQ had been validated.[9] Bullying involvement categorization into bullies, victim, bully–victims, and noninvolved was used for subgroup comparisons and calculation of prevalence. Descriptive statistics were used to portray the characteristics of various categories, and analysis of variance (ANOVA)/ Chi-square test was applied to determine the associations between various sociodemographic variables and bullying involvement categories.

RESULTS

Out of the 2,552 questionnaires distributed, 2,274 (89.1%) were returned. Proper categorization of bully/victim was possible in 2,182 (85.5%) responses, and these were subjected to further analysis. There were 845 girls and 1,334 boys, as shown in the sociodemographic profile [Table 1].

The prevalence of bullying involvement was 70%. Of the 2,182 participants, 199 (9.1%) were categorized as bullies, 406 (18.6%) as victims, 924 (42.3%) as bully–victims, and 653 (30%) as noninvolved. Analysis of the frequency of response on each question of the PIPSQ victim subscale found that teasing, making fun, taking things, and making feel sad were most frequently endorsed as "sometimes" or "a lot" [Table 2]. Analysis of the place of bullying reported by the victims was carried out in 1,330 participants. These participants were bullied in the absence of a teacher in the classroom (18.9%, $n = 252$), during the recess (26.6%, $n = 345$), during the prayer session (7%, $n = 97$), just after school (21%, $n = 279$), and on the way to home (12.6%, $n = 354$).

Only 33.5% ($n = 445$) had shared their experiences with parents/teachers and only 22.3% ($n = 297$) received some intervention by parents/teachers. In addition, 45.1% ($n = 985$) reported that they have observed other students being bullied, and 34.3% ($n = 749$) had tried to help the victims.

Bullying involvement was higher in boys (77.5%) compared with girls (58.3%) ($P < 0.01$). Victim experiences were also higher in boys (67.2%, 16.7% + 50.5%) compared with girls (51%, 21.5% + 29.5%) [Table 1]. The bully–victim experience was higher in boys (50.5%) compared with girls (29.5%). No association was found between other sociodemographic characteristics like family type, birth order, the number of friends, or grade in school with the bully, victim, or bully–victim category.

Table 1: Sociodemographic profile of the study participants and frequency distribution according to bullying-related categories

Variable (*n*)	Bully *n* (%)	Victim *n* (%)	Bully and Victim *n* (%)	Noninvolved *n* (%)	*P**
Gender (2179)					
Female (845)	62 (7.3)	182 (21.5)	249 (29.5)	352 (41.7)	<0.01
Male (1334)	137 (10.3)	223 (16.7)	674 (50.5)	300 (22.5)	
Family Type (1813)					
Joint (955)	80 (8.4)	197 (20.6)	396 (41.5)	282 (29.5)	0.212
Nuclear (560)	57 (10.2)	90 (16.1)	224 (40.0)	189 (33.8)	
Separated (298)	26 (8.7)	57 (19.1)	130 (43.6)	85 (28.5)	
Birth Order (1967)					
Eldest (782)	70 (9.0)	158 (20.2)	312 (39.9)	242 (30.9)	0.222
Youngest (709)	69 (9.7)	129 (18.2)	318 (44.9)	193 (27.2)	
In Between (476)	44 (9.2)	80 (16.8)	194 (40.8)	158 (33.2)	
Friends (2182)					
Up to 6 (820)	70 (8.5)	159 (19.4)	339 (41.3)	252 (30.7)	0.677
More than 6 (1362)	129 (9.5)	247 (18.1)	585 (43.0)	401 (29.4)	

**P* obtained using Chi-square test

The SDQ was used for appraisal of emotional, behavior, and interpersonal difficulties experienced. ANOVA was used to compare SDQ total and subscale scores of bullying involvement categories. There was a significant difference amongst the groups on total SDQ and all subscale scores. Post hoc testing was done, keeping the noninvolved group as reference. On post hoc testing, compared with the noninvolved group, the bully–victim group was most significantly affected. Bully–victim group had the highest level of total difficulty score, emotional problems, conduct problems, hyperactivity, and peer problems. They also scored lowest in the prosocial behaviors subscale. Compared with the noninvolved group, the victim group had significantly higher emotional and peer problems, whereas the bully group was not any different from the noninvolved group [Table 3].

DISCUSSION

The prevalence of bullying involvement among students of rural schools of Anand was 70%. This rate is slightly higher compared with the earlier study by Malhi *et al*. (53%)[3] using a similar methodology for screening and categorization. The prevalence is also much higher than the previous Anand/Vadodara urban school study (49%), contrary to our hypothesis. The Anand/Vadodara study utilized a different method for

Table 2: Victim experiences and bullying behaviors for the study population as measured by PIPSQ

PIPSQ Subscale Questions	Never Freq (%)	Sometimes Freq (%)	A lot Freq (%)
Victim experiences questions*			
1. Other students make me cry	1672 (76.6)	418 (19.2)	62 (2.8)
3. Other students take things from me that I do not want to give them	1561 (71.5)	475 (21.8)	124 (5.7)
5. Other students look at me in a mean way	1672 (76.6)	364 (16.7)	115 (5.3)
7. At recess, I play by myself	1716 (78.6)	339 (15.5)	94 (4.3)
9. Another student tells me they will hurt me	1730 (79.3)	336 (15.4)	80 (3.7)
11. I am hit or kicked by other students	1619 (74.2)	444 (20.3)	96 (4.4)
13. Other students tease me	1368 (62.7)	612 (28)	168 (7.7)
15. Other students ignore me on purpose	1656 (75.9)	363 (16.6)	123 (5.6)
17. Other students make me feel sad	1561 (71.5)	489 (22.4)	95 (4.4)
19. Other students make fun of me	1408 (64.5)	594 (27.2)	142 (6.5)
20. I want to stay home from school because students are mean to me	1844 (84.5)	222 (10.2)	84 (3.8)
22. Other students leave me out of games on purpose	1654 (75.8)	375 (17.2)	117 (5.4)
Bullying Behavior-related Scale Questions			
2. I tease other students	1426 (65.4)	649 (29.7)	84 (3.8)
4. I push or slap other students	1671 (76.6)	421 (19.3)	64 (2.9)
6. I tell other students I will hit or hurt them	1817 (83.3)	249 (11.4)	79 (3.6)
8. I say mean things about a student to make other kids laugh	1451 (66.5)	541 (24.8)	165 (7.6)
10. I make other students feel sad on purpose	1890 (86.6)	191 (8.8)	70 (3.2)
12. I call other students bad names	1703 (78)	373 (17.1)	71 (3.3)
14. I am mean to other students	1671 (76.6)	366 (16.8)	111 (5.1)
16. I hit or kick other students	1703 (78)	362 (16.6)	86 (3.9)
18. I feel bad because I am mean to other students	1473 (67.5)	452 (20.7)	222 (10.2)
21. I give other students mean or “dirty” looks	1914 (87.7)	173 (7.9)	61 (2.8)

*Frequency (%) does not add up because of a few missing values. PIPSQ=Peer Interaction in Primary School Questionnaire, Freq=Frequency

Table 3: Group-wise comparative means and SDs on SDQ

SDQ Subscale*	Bully	Victim	Bully-Victim	Noninvolved	*P***
Emotional Problems (*n*=2165)	3.49 (2.33)	4.23 (2.41)	4.29 (2.25)	3.72 (2.38)	<0.001
	0.686	0.009	<0.001	Reference	
Conduct problems (*n*=2166)	3.22 (1.94)	3 (1.97)	3.61 (1.97)	2.97 (2.28)	<0.001
	0.51	0.99	<0.001	Reference	
Hyperactivity (*n*=2165)	3.45 (2.34)	3.56 (2.39)	3.94 (2.19)	3.30 (2.47)	<0.001
	0.89	0.40	<0.001	Reference	
Peer ProblemtZ s (*n*=2162)	3.36 (1.88)	3.70 (1.90)	3.86 (1.84)	3.32 (2.09)	<0.001
	0.99	0.02	<0.001	Reference	
Prosocial (*n*=2174)	7.85 (2.12)	7.73 (2.02)	7.27 (2.13)	7.82 (2.21)	<0.001
	0.99	0.94	<0.001	Reference	
Total Difficulty Score (*n*=2143)	13.53 (6.46)	14.45 (6.21)	15.71 (6.04)	13.26 (7.30)	<0.001
	0.97	0.04	<0.001	Reference	

*The second row in each cell represent *post hoc P* value with reference to noninvolved. **P-value obtained using analysis of variance test. SDQ: Strengths and Difficulty Questionnaire

screening and categorization of bullying involvement behaviors (the segregation into the victim, bully, and bully–victim was done based on two SDQ questions, viz. "Other people or young children pick on me or bully me" and "I fight a lot. I can make other people do what I want."[6] A study done in Brazil found that the prevalence of bullying was 17.6%.[11] These findings combined suggest that bullying involvement is a significant unaddressed problem in rural schools of Anand.

The Health Behavior in School-Aged Children (HBSC) survey 2005/06 was conducted in the sixth, eighth, and tenth-grade school children from 40 countries. It found that 10.7% of participants were bullies, 12.6% were victims, and 3.6% were bully–victims.[12] Our findings were comparable, with 9% of participants being bullies and 19% being victims. However, 42% were bully–victims. Malhi *et al*. had, in an urban study, found 13% bullies, 19.2% victims and 20.6% bully–victims.[3] The Anand/Vadodara urban school study found 19.3% bullies, 19.1% victims, and 10.6% bully–victims.[6] Other studies have reported victim rates from 30% to 60%.[4,5] The high proportion of bully–victims in this sample is a stark difference compared with the previous urban studies. Variations in rates may be explained by certain rural factors like:

a. Closeness of the children's habitat (such that everyone is often into everyone else's business
b. Rural children are more likely to be exposed to domestic violence and abuse
c. Rural children are more likely to be exposed to and role model substance use
d. Lack of bullying prevention programs.

Variation in rates may also be because of differences in methodologies and threshold used for screening the study sample. The high proportion of bully–victims in our study may not be a chance finding, because the psychosocial profile of this group measured using the self-reported SDQ matches with characteristics previously reported in the literature ("hyperactive, impulsive, experiencing more peer rejection, more academic difficulties, and more stressful and harsh home environments").[13] On the SDQ profile, bully–victims were the worst affected group compared with the noninvolved, scoring the highest mean on emotional problems, conduct problems, hyperactivity, and peer problems, and the lowest mean on prosocial behavior. The high scores on the hyperactivity and peer problems subscales are self-explanatory, whereas impulsivity is usually a component of conduct problems, and stress can be hypothesized as a contributor to emotional problems.

Our study also shows that boys had higher bullying perpetration and victim experiences. Boys showing higher victim experiences are contrary to earlier research, where girls were found more likely to be victims,[3,4,13] but consistent with the findings of Anand/Vadodara urban school study.[6] In the Anand/Vadodara urban school study, it was found that students having fewer friends ($P = 0.001$), overweight/obese ($P = 0.02$), and boys ($P < 0.001$) were more likely to be victims. The urban study also found an association between bullying perpetration and poor academic performance. Differences, as compared with the urban study, were that the bully or victim category was not found to be associated with the number of friends or scholastic performance.

Teasing, making fun, taking things, and making feels sad were the most frequently reported experiences by victims. These findings are similar to the previous Anand/Vadodara urban school study.[6] Earlier studies have also similarly reported calling names, threatening, making fun and physical bullying as being the most frequent.[3-5] These findings need to be taken into consideration for the future design of local prevention policies and intervention programs.[4]

Bullying was observed in situations where the teacher was not present or it is difficult to monitor for the teacher, for example, in recess and prayer sessions. Earlier studies had reported that most of the bullying took place in the classroom when the teacher was not present during recess, in the hallways, and playgrounds.[3,4]

Only one-third of the victims (33.5%) shared their experience with parents/teachers, whereas, in earlier studies, it was none[5] to minimal (3.8%).[3] Out of those who shared their experiences with parents/teachers, about 66% received some intervention by parents/teachers. Ramya *et al*. reported that about 59% received intervention by teachers in the form of punishment for the bully.[4] An epidemiological survey on mental health problems of adolescents in Anand district had found that difficulty in discussing friends with parents was one of the factors that increased odds of having a mental health problem.[7]

No significant correlation was found between bullying-related categories and other socio-demographic variables [Table 1]. Nonassociation with the grade in school may indicate the stability of the victim experience (e.g. "once a victim, always a victim"). While literature[13] has reported that bullying is evident as early as in preschool, it remains unknown how early does peer bullying begins in the Indian population, and this requires further exploration.

When means of prosocial behaviors and total-difficulties on the SDQ profile for the bully group are compared

with the noninvolved group, they appeared equally socially competent. This phenomenon has been described in the literature as 'socially integrated bullies' who are difficult for adults to recognize as they appear to be socially competent and well-functioning individuals.[13]

The use of previously validated strategies for case finding, large sample size, use of SDQ, evaluation of bystander behavior, and evaluation of help-seeking were strengths of this study. Bias in reporting by the participants, noninclusion of other anthropometric measurements, lack of validation of the translated version of PIPSQ in our population, and limited generalizability are some limitations of the study.

CONCLUSIONS

Take-home messages and implications of our study are:

a. There is high prevalence of bullying-related involvement, with high proportion of the bully–victims compared with earlier studies
b. There is a complete lack of bullying prevention policies at school level
c. Local profile of bullies, victims, bystanders, and parents/teacher needs to be taken into consideration for designing future intervention program
d. A simple screening strategy, using a few questions to identify bullying involvement, is valid and useful.

Variations in the prevalence rates between studies may mainly be because of differences in methodologies and threshold used for screening the population. Thus, it is recommended that a core group of experts should define guidelines to standardize future bullying-related research in India.

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Conflicts of interest
There are no conflicts of interest.

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Original Article

The Effectiveness of Nurses Implemented Music Add-on Therapy in Children with Behavioral Problems

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ABSTRACT

Background: Increasing rates of behavioral problems among children in India necessitates newer ways of managing them with medical and nonmedical approaches. Music add-on therapy is a method for treating mental disturbances. This study examines the effectiveness of music add-on therapy in managing children with behavioral problems. **Methods and Materials:** A randomized controlled design was adopted with a random allocation of 40 children (20 each in experimental and control groups) aged between 6 and 12 years with behavioral disorders as per the International Statistical Classification of Diseases and Related Health Problems (ICD)-10. After the pretest, both the groups received treatment as usual (TAU), while the experimental group alone additionally received music add-on intervention with eight Hindustani ragas for 3 weeks. As clinical outcome measures, we used the Childrens Global Assessment Scale, Nisonger Child Behavior Rating Form typical IQ (NCBRF-TIQ) version, and visual analogue scale (VAS) for a parent to monitor the behavioral improvement. **Results:** Children exposed to the music add-on therapy had improved score in the Children Global Assessment Scale (CGAS) and the VAS as compared with the control group ($F[2,76] = 34.307$, $P < 0.001$ and $F[2,76] = 72.4$, $P < 0.001$, respectively). Further, the NCBRF-TIQ version revealed improvement in positive social behavior ($F[2,76] = 13.089$, $P < 0.001$) and reduction in problem behaviors in the experimental group. **Conclusion:** Music add-on therapy is effective in improving positive social behavior and reducing problem behaviors among children.

Key words: *Behavioral, child, music, nurse, therapy*

Key messages:

- *Nurse Implemented Music Add-on Therapy (NIMAT) was effective in improving positive social behavior and reducing problem behaviors among children with a behavioral problem.*
- *NIMAT is an effective alternative, complementary method to manage children with behavioral problems along with the regular treatment implemented by the nurses.*

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Behavioral disorders are generally classified into externalizing disorders or disruptive behavior disorders. Temper tantrums, oppositional behavior, argumentativeness, aggression, etc., are common features in children with externalizing disorders. These disorders include attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), and conduct disorder (CD). These disorders interfere with the school performance and family and peer relationships of the children and usually intensify over time.[1-3]

Incidence and prevalence of behavioral disorders

According to the World Health Report (2000), the prevalence of child psychiatric disorders was 14–20%. A study conducted by Srinath *et al*.[4] in Bangalore, India reported that the prevalence rate of child and adolescent psychiatric disorder in the community was 12%.

Mukhopadhyay *et al*.[5] reported 15.5% of CDs and ADHD in Kolkata. Sarkhel *et al*.[6] reported that the prevalence of CD and ODD among school children at Kanke, Ranchi, India were 4.58% and 4.8%, respectively. According to Suvarna and Kamath,[7] the prevalence of ADHD in Mumbai was 12.2%.

The National Mental Health Survey of India, 2015–16,[8] reported that the prevalence of mental disorders in the age group 13–17 years was 7.3% and nearly equal in both genders. The prevalence of CDs, including ODDs, among adolescents, was found to be 0.8%.

Gupta[9] reported that 22.7% of children showed behavioral, cognitive, or emotional problems, and a higher prevalence of externalizing symptoms was noticed among boys.

The growing number of children with behavioral problems is a significant concern for mental health nurses. Cost-effective nonpharmacological therapies are the need of the hour. This study is an attempt to use music as an add-on therapy to manage children with behavioral problems, with the hypothesis that Nurse Implemented Music Add-on Therapy (NIMAT) improves positive behavior in children.

Listening to music – An approach to manage behavioral problems

There are several medical and nonmedical approaches suggested for the treatment of behavioral disorders. Listening to music is one of the nonmedical approaches. As the adage says, "music calms the savage beast," children also calm down with music.[10]

De *et al*.[11] conducted a case study to see the effects of music therapy on young children's challenging behaviors. They found that music therapy decreased problem behavior and increased alternative behavior in participants. Similarly, Choi *et al*. (2010)[12] reported that group music intervention reduced aggression and improved self-esteem among school-going children.

Robb[13] conducted a study on designing music therapy interventions for hospitalized children and adolescents, using a contextual support model of music therapy. The author explains how music functions to create supportive environments and, in turn, promotes active coping behaviors among children and adolescents.

Jesna *et al*.[14] studied the effectiveness of selected ragas in music in managing children with aggression. Shankarabaranam musical raga was administered for 20 min every day to the experimental group, in addition to the regular treatment, for 2 weeks. Modified Overt Aggression Scale (MOAS)[15] was used to assess the level of aggression. The study concluded that music was an effective tool in engaging children with aggression.

Nurses play a vital role in the management of childhood behavioral disorders. Nurses have a greater opportunity to spend more time with the children admitted to the child psychiatry centre (CPC) and their parents while providing nursing care. Hence, an attempt was made by the researcher to experiment with music add-on therapy through the nurses to reduce the behavioral problems of children admitted to the CPC.

METHODS AND MATERIALS

A randomized controlled design was adopted in this study. Children with disruptive behavioral disorders (ADHD, ODD, or CD) based on the International Statistical Classification of Diseases and Related Health Problems (ICD)-10,[16] admitted in the CPC) of the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore were randomly allotted to the experimental and control groups (20 in each group). Assuming a 5% level of significance and 80% power, with a standard deviation (SD) of 13.65, and a mean difference of 10 in Disruptive Behavior Subscale (DBS) scores (D-total), the minimum sample size required was 15. Expecting a dropout of 20%, the required sample size was 18 and we rounded it to 20 in each group.

Both male and female children in the age group 6–12 years were included. Children with pervasive developmental disorder (PDD) as per ICD-10, comorbid mood/anxiety/psychotic disorders, or visual or hearing impairment were excluded from the study.

The subjects were allocated to the experimental or control groups based on a random sequence generated prior to the study. The nurses explained the add-on music intervention to the parents of children admitted in the CPC and the children were allotted to the experimental or control group. The total duration of the project was 1 year from July 2017 to June 2018.

The control group received treatment as usual (TAU) as prescribed by the treating team. The experimental group received TAU and NIMAT Music Intervention. In this study, TAU refers to the routine pharmacological and psychosocial management protocol used for children with behavioral disorders in the unit.

The music module and intervention

The ragas in Indian classical music are categorized as Hindustani ragas and Carnatic ragas. Hindustani ragas are followed in North India, whereas carnatic music is famous in South India. In the present study, Hindustani Ragas were selected and validated by the investigators. The panel of experts involved in the preparation of the music module of NIMAT included a psychiatrist, a nursing consultant in the child and adolescent psychiatry unit, and a music expert with a doctorate in music and running a music foundation.

The music module was prepared with the help of professionally qualified expert singers in a state-of-the-art private music theatre. A total of eight ragas were composed and compiled into the module (in a compact disc [CD] format). The ragas used in this module were Mishra Khamaj – Kalyan, Gorakh Kalyan, Bhairav, Bihag, Miya-Malhar, Malkouns, Marwa, and Desh. These ragas focus on admiration of nature, harmony with nature, worshiping the creator of the universe, the importance of a teacher in life, and the mother–child bonding. The total duration of the CD module was 45 min.

The experimental group received the complete music module as an add-on with TAU, whereas the control group received only TAU. Four ragas, namely Mishra Khamaj–Kalyan, Gorakh Kalyan, Bhairav, and Bihag, were played in the morning for about 25 min, and the remaining four ragas, Miya-Malhar, Malkouns, Marwa and Desh were played in the evening, through a music system, for about 20 min, in a room identified for this project at the CPC. The first and second authors trained the nurses in the CPC to administer the add-on music intervention module. Specific instructions were provided to the nurses on bringing the child, accommodating the children on a mat, handling the children in the music therapy room, including a parent if necessary, and handling disturbed children. Nurses were also trained to operate the CD player and in the sequence of playing the audio/ragas.

A separate file was created for each child assigned in the project, with the coding sequence for experimental (E01 to E20) and control (C01 to C20) group separately. Each file had consent and assent proformas, followed by the demographic/clinical datasheet and different sets of the assessment tools used in each assessment. A log sheet was kept to enter the details of the attendance of the child entering the NIMAT. The monitoring nurse marked the attendance with a signature. The children in the experimental group listened to music for 2 to 3 weeks to achieve the desired number of sessions.

Six parents refused to give consent for the music add on therapy, and 28 dropped out (experimental-19, control- 9) due to early discharge.

Research tools and data collection method

The demographic/clinical profiles of the children were collected through the demographic/clinical proforma.

The Children Global Assessment Scale (CGAS) assessed the overall functioning of the children.[17] The CGAS is coded based on the client's worst level of emotional and behavioral functioning on a hypothetical continuum of health and illness. The scores can range from 1, which is the very worst, to 100, which is the very best. The test-retest reliability value of the CGAS is 0.85.

The behavioral improvements were measured through the Nisonger Child Behavior Rating Form typical IQ (NCBRF-TIQ) version.[18] This scale has two domains. The first domain is a single positive social behavior subscale (10 items), and the second domain has six problem behavior subscales (54 items): (i) Conduct problems, (ii) Oppositional, (iii) Hyperactive, (iv) Inattentive, (v) Withdrawn/Dysphoric, and (vi) Overly sensitive. The internal consistency (alpha]=) is 0.77–0.95.

The Visual Analogue Scale (VAS) for parents is a 10-point scale to monitor the improvement. It provides the overall impression the parent has on the behavior of the child. It helps the parent to locate the level of improvement in the child's behavior on a scale of 0–10.

In this study, the scores of CGAS, NCBRF-TIQ, and VAS (parent) were considered as the primary outcome measures.

Prior to the administration of music intervention, the baseline assessment was carried out on the experimental and control groups through demographic proforma, CGAS and NCBRF-TIQ Subsequently, the NIMAT

module was administered to the children in the experimental group. Children in the experimental group received the music inputs from the third or fourth day of admission, for about three weeks, in small groups of 4 to 6 children. Further data were collected from both the groups on the 8th and 16th days.

Ethics approval

Ethical principles were strictly followed by obtaining the institute's ethical committee clearance and permission. Written informed consent from parents and informed assent from children were obtained. The subjects were assured of the confidentiality of the data. Due to the ethical considerations, at the end of the study, children of both the groups were offered the module CD free of cost to listen at home.

Data analysis

All the statistical analyses were done using the Statistical Package for Social Sciences (SPSS) software version 22.0 (IBM SPSS Statistics for Windows, Armonk, NY: IBM Corp). The normality assumption of data was tested using the Shapiro–Wilk test. Further, repeated measures analysis of variance (RM ANOVA) was used to compare the changes in the various outcome measures over different times of assessment between the study groups. Typically, ANOVA is robust to violations of assumptions of normality with homogeneous variance among groups. Moreover, inter-correlations among the means in repeated measures designs assume greater power than between-group designs.[19] Spearman's rho correlation coefficient test was used to find the relationship between the subdomain scores in NCBRF-TIQ scale. The level of significance was fixed at 5%.

RESULTS

The socio-demographic and clinical profile of the children

The mean age of children in the experimental and control groups was nine years and eight years, respectively. Most of them were male (95% in the experimental group and 60% in the control group). Most of them were from the monthly income group of Rs 10,001-50,000 and hailed from an urban background. The majority of the children in both groups were attending regular schools. In both groups, more than 90% of the children were living with parents and were born from nonconsanguineous marriages [Table 1].

Considering the clinical profile of the children, ADHD was the most common diagnosis in both the experimental and control groups. Very few of them had a provisional diagnosis of emotional disorder, epilepsy, tic disorder, or obsessive-compulsive disorder (OCD). There were no initial group differences in this regard [Table 2].

Table 1: Distribution of socio-demographic profile by study groups

Socio-demographic Variables	Experimental Group (*n*=20) frequency (%)	Control Group (*n*=20) frequency (%)
Age (in years)*	9.00 (1.75)	8.00 (2.41)
Sex		
Male	19 (95)	12 (60)
Female	01 (05)	08 (40)
School		
Attending	16 (80)	13 (65)
Not attending	04 (20)	07 (35)
Type of School		
Play School	01 (05)	04 (20)
Regular School	18 (90)	12 (60)
Special School	01 (05)	04 (20)
Monthly Family Income (Rs)		
<10,000	06 (30)	02 (10)
10,001-50,000	08 (40)	16 (80)
50,001-1,00,000	04 (20)	02 (10)
More than 1,00,000	02 (10)	00 (00)
Socio- economic Status		
Low	03 (15)	02 (10)
Middle	12 (60)	17 (85)
Upper	05 (25)	01 (05)
Domicile		
Urban	12 (60)	14 (70)
Rural	08 (40)	06 (30)
Living Arrangements		
Living with parents	18 (90)	20 (100)
Living with relatives or caregivers	02 (10)	00 (00)
Type of Family		
Nuclear	08 (40)	16 (80)
Joint	11 (55)	04 (20)
Extended	01 (05)	00 (00)
Type of Marriage		
Consanguineous	01 (05)	02 (10)
Nonconsanguineous	19 (95)	18 (90)

*Mean (Standard deviation)

Table 2: Distribution of clinical profile by study groups

Diagnosis	Experimental Group (*n*=20) frequency (%)	Control Group (*n*=20) frequency (%)
ADHD	20 (100)	19 (95)
ODD	01 (05)	04 (20)
CD	00 (00)	01 (05)
Provisional diagnosis during admission		
Emotional Disorder	03 (15)	00 (00)
Tic Disorder	03 (15)	00 (00)
Epilepsy	01 (05)	02 (10)
OCD	01 (05)	00 (00)
Others	02 (10)	00 (00)

ADHD – Attention Deficit Hyperactive Disorder, ODD – Oppositional defiant disorder, CD – Conduct disorder, OCD – Obsessive Compulsive Disorder

Changes in outcome measures - CGAS, VAS, and NCBRF-TIQ Scores

Children exposed to music add-on therapy have improved scores in the CGAS in comparison with the control group [Table 3 and Figure 1]. This finding shows that there is an overall improvement in the behavior of children subjected to the experiment.

The VAS assessment of parents showed that children exposed to music add-on therapy have a greater behavioral improvement in comparison with the control group [Table 3 and Figure 2].

Assessment of children in the experimental and control groups with the NCBRF-TIQ revealed that positive social behavior has significantly improved in the experimental group [Table 4 and Figure 3]. There was an overall reduction in the Domaine-2 scores of NCBRF-TIQ, such as oversensitivity, oppositional behavior, conduct problem, hyperactivity, inattentiveness, withdrawn, and dysphoric behavior among the children exposed to the music add-on therapy when compared with the control group.

The children exposed to music showed improvements in all the subdomains. The problem behavior was significantly reduced in disruptive behavior (D-Total) scores as well as the hyperactivity and inattention (ADHD-Total) scores [Table 4 and Figures 4, 5].

There was a strong positive correlation between disruptive behavior (D-Total) and the hyperactivity and inattention (ADHD-Total) scores at the baseline assessment ($r = 0.6$, $P < 0.01$ in Spearman's ρ-correlation coefficient test).

Children were cooperative for music therapy, and some of them felt comfortable with the presence of their parents. More than 60% of the parents in the experimental group disclosed that with the introduction of music, sleep improved and restlessness came down in their children.

DISCUSSION

This study was an attempt to use music as an add-on therapy to manage children with behavioral problems with the hypothesis that NIMAT improves positive behavior in children.

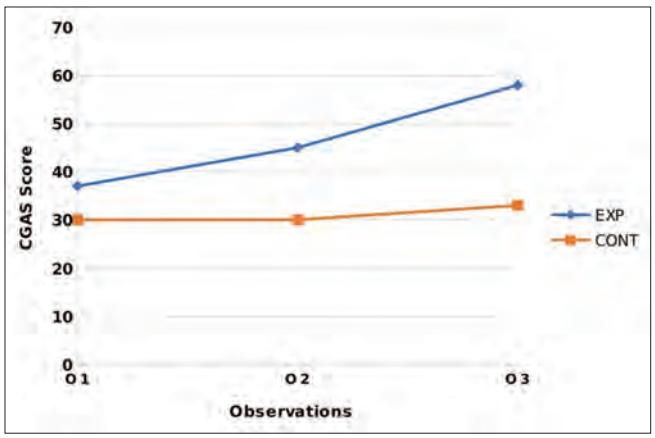

Figure 1: Graphical representation of global functioning of the children through the children global assessment scale

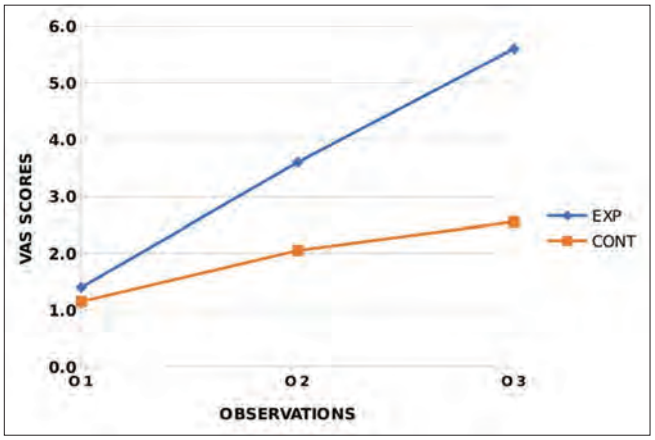

Figure 2: Graphical representation of behavioral improvements through parent visual analogue scale

Table 3: Assessment of Global functioning of the children through CGAS and parent VAS

Measure	Group	Mean (SD)			*F* - Statistics *F* (2,76)	*P*	Partial Eta Squared
		Pretest O-1	Post Test 1 O-2	Post Test 2 O-3			
CGAS	Experimental Group (*n*=20)	37.0 (13.3)	45.0 (12.18)	58.1 (10.15)	34.307	<0.001	0.474
	Control Group (*n*=20)	30.0 (17.28)	29.95 (16.31)	32.90 (14.33)			
VAS	Experimental Group (*n*=20)	1.40 (1.09)	3.60 (1.66)	5.60 (1.78)	72.353	<0.001	-
	Control Group (*n*=20)	1.15 (0.48)	2.05 (0.94)	2.55 (1.05)			

CGAS – Children Global Assessment Scale, VAS – Visual analogue scale, SD – Standard deviation

Table 4: Assessment of children behavior through NCBRF-TIQ version

Domains	Group	Mean (SD)			*F* - Statistics *F* (2,76)	*P*	Partial Eta Squared
		Pretest O-1	Post Test 1 O-2	Post Test 2 O-3			
D1 (Positive social behavior)	Experimental Group (*n*=20)	8.15 (4.69)	10.20 (5.79)	15.95 (6.63)	13.089	<0.001	0.256
	Control Group (*n*=20)	4.65 (4.79)	6.85 (5.36)	7.65 (5.01)			
D2 (Disruptive Behavior) D-Total	Experimental Group (*n*=20)	35.6 (13.73)	24.8 (12.97)	17.3 (10.88)	16.512	<0.001	0.303
	Control Group (*n*=20)	28.7 (18.06)	25.65 (15.54)	22.0 (12.70)			
D2 (Hyperactivity and Inattention) ADHD-Total	Experimental Group (*n*=20)	22.60 (6.45)	16.65 (6.45)	14.05 (6.88)	12.534	<0.001	0.248
	Control Group (*n*=20)	24.60 (5.11)	23.50 (4.81)	21.75 (4.43)			

NCBRF-TIQ – Nisonger Child Behavior Rating Form typical IQ, SD – Standard deviation, ADHD – Attention deficit hyperactivity disorder

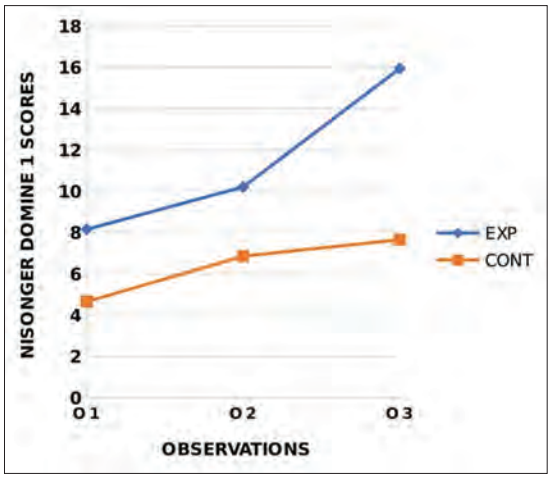

Figure 3: Graphical representation of Nisonger-D1: Positive Social Behavior

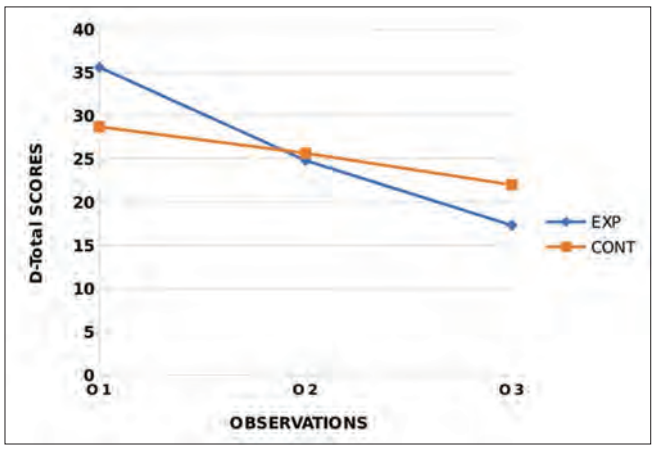

Figure 4: Graphical representation of Nisonger-D2: Disruptive Behavior Subscale Scores (D-Total)

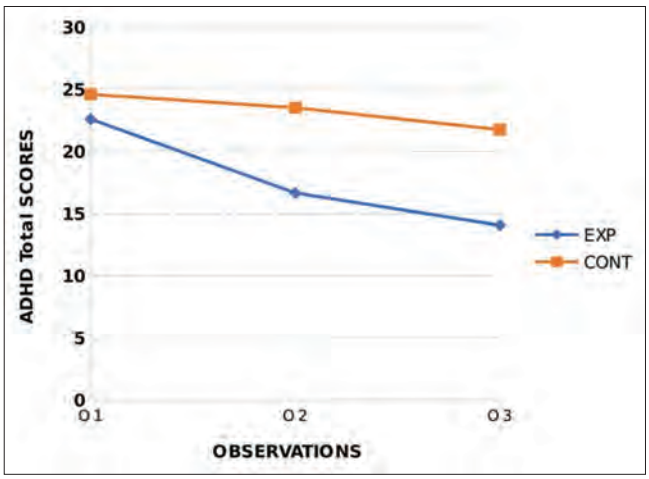

Figure 5: Graphical representation of Nisonger-D2: Hyperactivity and Inattention Subscale Scores (ADHD-TOTAL)

The results obtained through CGAS, NCBRF-TIQ, and the VAS proves that music intervention is effective in managing children with behavioral issues. Listening to music brought behavioral changes in the children probably due to the calming and soothing effects of music, diversion from intruding thoughts, and reduction in restless activity.

NCBRF-TIQ revealed that positive social behavior improved and the problem behavior reduced significantly in the experimental group. This finding is similar to that reported by De *et al*.,[11] who concluded that music therapy decreased problem behavior and increased alternative behavior. Similarly, Choi *et al*.[12] reported that group music intervention reduced aggression and improved self-esteem among school-going children.

There are not many studies from India on music as a therapeutic tool for children with mental illness, especially behavioral problems. It is important to note that music add-on therapy has a positive effect on all the subdomains of the behavior assessment.

Relevance for clinical practice

Nursing care for children with behavioral disorders is always a challenge in any setting. The nursing initiatives with nonpharmacological management is a welcome step in order to reduce the side effects of medication, improve treatment adherence, and to manage these children at home after discharge. Nurses have greater access to the children admitted in child psychiatry units; hence, they are the best positioned to implement music therapy for the inmates. The preparation of the music module, training the nurses to implement such a module, operating a CD player for playing the music and identifying a calm room for the same are manageable in terms of cost. Nurses shall make an activity schedule for the children in child psychiatry wards and accommodate the music listening into it.

Implications for future research

Live music and active involvement of the participants with musical instruments may be tried. Biological, biochemical, and electrophysiological changes may be assessed along with the behavioral outcomes with music therapy. A longitudinal study with the music module, including tele follow up may also be considered for future research.

Limitations

The study findings are from inpatients of a tertiary care CPC. Hence, generalization to all the settings may not be possible. The outcome measures mainly depended on the parental version/response, which may not reflect the actual improvements in the child's behavior. The current music module had an option for passive listening only; the possibility of active involvement, such as singing along with the musical track or using instruments, was

not there. Due to the limited sample size, the effect of comorbid disorders could not be explored.

CONCLUSION

The NIMAT is effective in improving positive social behavior and reducing problem behavior among children with behavioral problems and an effective alternative, complementary method to manage children with behavioral problems along with the regular treatment.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Serum Lipids among Drug Naïve or Drug-Free Patients with Obsessive Compulsive Disorder and their Association with Impulsivity: A Comparative Study

Purvi Vats, Basudeb Das, Sourav Khanra

ABSTRACT

Background: The derangement of serum lipids is well documented in psychiatric disorders like schizophrenia, mania, and depression but not in obsessive compulsive disorder (OCD), where it has been inadequately examined. Also, serum lipid abnormalities are increasingly found in "impulsivity," an important sub-construct of OCD. Our study aimed to examine serum lipid profile among patients with OCD and its association with clinical profile and impulsivity among them. **Methods:** Forty drug naïve or drug-free (four weeks for oral and eight weeks for any depot psychotropics) patients with OCD according to International Classification of Disease -10th version (ICD-10): Diagnostic Criteria for Research (DCR) by the World Health Organization (WHO), from outpatient and inpatient departments of a tertiary care psychiatric hospital were recruited. Measures like Yale–Brown Obsessive Compulsive Scale (Y-BOCS), Hamliton Rating Scale for Depression (HAM-D), Barratt's Impulsivity Scale (BIS-11), and Hamilton Rating Scale for Anxiety (HAM-A) were administered. Forty age and sex-matched healthy controls (HC) were recruited after screening with General Health Questionnaire 12 (GHQ-12). Serum lipids were assessed in both the groups. **Results:** Serum high density lipoproteins (HDL) ($P < 0.001$; partial $\eta^2 = 0.176$) and apolipoprotein B ($P < 0.001$; partial $\eta^2 = 0.531$) were significantly higher in OCD group than age- and sex-matched HC. A trend toward lower serum HDL ($P = 0.06$; partial $\eta^2 = 0.060$) was observed among patients of OCD with high impulsivity. Serum HDL was negatively correlated with BIS attention ($r_s = -0.32$; $p = 0.03$), BIS motor ($r_s = 0.40$; $P = 0.01$), BIS non-planning ($r_s = -0.36$; $P = 0.02$), and BIS total ($r_s = -0.36$; $P = 0.01$) scores. Serum triglycerides (TG) ($r_s = 0.34$; $P = 0.03$) and apolipoprotein B ($r_s = -0.32$; $P = 0.04$) were negatively correlated with Y-BOCS compulsion score. Serum TG ($r_s = -0.45$, $P < 0.01$) and serum very low density lipoprotein (VLDL) was negatively ($r_s = -0.39$; $P = 0.01$) correlated with Y-BOCS total scores. Serum VLDL was positively ($r_s = 0.34$; $P = 0.03$) correlated with BIS motor scores. **Conclusions:** Serum lipid fractions are deranged among patients with OCD. Different lipid fractions have different associations with clinical profiles of OCD. Impulsivity among patients with OCD may have a specific association with

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serum lipids. A small sample size, use of self-report measure without adaptation for impulsivity, a lack of metabolic profile assessment among participants, and a lack of assessment of impulsivity among HC were the limitations of our tudy.

Key words: *Impulsivity, lipids, obsessive-compulsive disorder, OCD*
Key Messages: *Serum lipids are deranged in OCD. Serum lipids are also varyingly correlated with impulsivity and severity of OCD.*

Impulsivity is defined as a predisposition for reacting to stimuli in a rapid and unplanned fashion with a reduced concern of the potential consequences.[1,2] The construct of impulsivity is multifaceted,[3,4] impulsivity manifests as "actions which are poorly conceived, prematurely expressed, unduly risky or inappropriate to the situation and that often result in undesirable consequences."[5] Patton *et al*.[6] described three main impulsivity sub-traits, namely motor impulsiveness, defined as acting without thinking, cognitive impulsiveness, characterized by making quick cognitive decisions, and non-planning impulsiveness, characterized by present orientations or a lack of "futuring." Higher attentional/cognitive impulsivity sub-construct is a demonstrated risk factor for several psychological consequences.[7]A growing body of evidence highlights the potential implication of impulsivity in obsessive-compulsive disorder (OCD), which affects between 0.3 and 3.1% of the general population and places enormous personal, social, and economic burden on society. For example, a few studies examining trait impulsivity in OCD have found that OCD patients show higher attentional, motor, and non-planning impulsivity than healthy controls (HC) .[8] Individuals with OCD, compared to HC, tend to make risky decisions, favoring options that provide large initial rewards but ultimately lead to a disadvantageous outcome.[9] This consistent pattern of irrational responding might reflect an exacerbated anticipation for a reward.[10]

The neurobiological basis of impulsivity has received considerable attention in recent years, in terms of both the anatomical as well as neurochemical foundations.[11-14] Deficient central serotonergic transmission has been proposed as a biological substrate for impulsivity,[15] and a few studies have suggested serum cholesterol to be a surrogate marker for the same and demonstrated a correlation.[16] A few studies have looked into the biochemical foundations of impulsivity in psychiatric disorders. Buydens–Branchey *et al*.[17]suggest that the most important lipid fraction is high-density lipoprotein (HDL), whereas others[18] propose total cholesterol (TC) or the low-density lipoprotein (LDL) fraction to be the important one. The proposal that even the sub-constructs of impulsivity might have different biological underpinnings[19] led to studies exploring the relationship between the former and various cholesterol fractions, and between serum cholesterol and various measures of impulsivity across psychiatric diagnoses. The association was found in patients with schizophrenia,[20] major depressive disorder,[17] bipolar disorder,[21] and substance use.[22] Although derangements of lipid profile in psychiatric illnesses have been studied, as per our best of knowledge, research on the same among patients with OCD and its relationship with impulsivity have not been examined. Hence, this study was conducted with aims and objectives 1) to examine serum lipids among patients with OCD and to compare with age- and sex-matched HC, 2) to examine and compare serum lipids between OCD with high impulsivity and OCD with low impulsivity, and 3) to examine the correlation among clinical profiles of OCD, impulsivity, and serum lipids.

METHODS

Participants

The study was a hospital-based cross-sectional study conducted at the outpatient(OPD) and inpatient department (IPD) of a tertiary care psychiatric hospital in India. Participants were selected with the purposive sampling method. Patients fulfilling inclusion and exclusion criteria during the study period, from May 2018 to January 2019, were recruited. Thus, the study group (cases) comprised of 40 patients of both sexes, aged 18–60 years, who had given informed consent, having primary diagnosis of OCD according to International Classification of Disease 10th Version (ICD-10), Diagnostic Criteria for Research (DCR) by World Health Organization (WHO),[23] and who were drug naïve or not on psychotropics for last four weeks (eight weeks in case of depot anti psychotics). Patients with comorbid physical illness like diabetes mellitus, liver disease, renal disease, hypertension, thyroid dysfunction, etc.; those who were on lipid-lowering agents, oral contraceptives or beta blockers; and those with comorbid psychiatric illness fulfilling ICD-10 DCR[23] or with psychosis were excluded. The control group comprised 40 age-and sex-matched healthy individuals who had scored less than 3 on the General Health Questionnaire (GHQ-12)[24] and had given informed consent.

Tools

Socio-demographic datasheet

Socio-demographic information was collected in a pre designed, semi-structured socio-demographic proforma.

Yale-brown obsessive-compulsive scale (Y-BOCS)[25]

This rating scale is designed to rate the severity and type of symptoms in patients with OCD. In general, the ratings depend upon the patient's report; however, the final rating is based on the clinical judgment of the interviewer.

Barratt's impulsiveness scale-11 (BIS-11)[6]

It is the most commonly used self-report measure for assessing impulsivity in both clinical and research settings. Original English version of the scale without any adaptation was used for the study. The subscales were introduced into the scale in its version 10, in the recognition of the multi dimensional nature of impulsivity, which became evident after factor analytic studies. BIS 11 is a further improvement on that, with the labeling of the "Attentional Impulsiveness" subscale, defined as an inability to focus attention or concentrate. In the BIS 11, there are 30 personal statements designed to assess general impulsiveness,[6] considering the multi-factorial nature of the construct. Items are rated from 1 (absent) to 4 (most extreme), and scores range from 30 to 120. The BIS 11 identifies three components of impulsivity, namely attentional/cognitive impulsivity, motor impulsivity, and non-planning impulsivity.

Hamilton rating scale for depression[26]

The HDRS is the most widely used clinician-administered depression assessment scale. The original version contains 17 items (HDRS17) pertaining to the symptoms of depression experienced over the past week. The HDRS was originally developed for hospital inpatients, thus the emphasis on melancholic and physical symptoms of depression. A later 21-item version (HDRS21) includes four items intended to subtype the depression.

Hamilton anxiety rating scale (HAM-A)[27]

It was one of the first rating scales developed to measure the severity of anxiety symptoms and is still widely used today in both clinical and research settings. The scale consists of 14 items, each defined by a series of symptoms, and measures both psychic anxiety (mental agitation and psychological distress) and somatic anxiety (physical complaints related to anxiety).

General health questionnaire 12[24]

General Health Questionnaire (GHQ) is the most common assessment tool of mental well-being. Developed as a screening tool to detect those likely to have or be at a risk of developing psychiatric disorders, it is a measure of the common mental health problems/domains of depression, anxiety, somatic symptoms, and social withdrawal. GHQ 12 has been used most widely in other working populations, allowing for more valid comparisons.

Data collection

After obtaining ethical permission from the institutional ethical committee, drug naïve patients from OPD and IPD of this institute, fulfilling inclusion and exclusion criteria, were selected. Those who gave informed consent were recruited for the study. The socio-demographic information was recorded.Y-BOCS, BIS -11, HAM-D, and HAM-A were administered on each recruited patient. A sample of 5 ml of venous blood was collected between 8 am and 9 am, after ensuring that the subjects have fasted for 12 hours. The blood sample was analyzed on the same day, within two hours of collection, during which the sample was stored at room temperature. Serum TC, HDL, LDL, very low-density lipoprotein (VLDL) and triglyceride (TG) estimation was done by an enzymatic method (using cholesterol esterase, cholesterol oxidase, and peroxidase). Apolipoproteins (Apo) A1 and B fractions were measured using immunoturbidometry.

Age and sex-matched healthy controls were selected through local advertisement, from the hospital staff. GHQ 12 was administered to check the eligibility for inclusion in the study. Serum lipids were measured following the protocol mentioned above.

Statistical analysis

Data were analyzed with Statistical Package of Social Science Version 25 (SPSS) for Windows. The frequency counts of the categorical variables were done and compared using the Chi-square test. Multivariate analysis, considering age in years as a covariate was performed to compare means between the groups. Partial $\eta^2$was calculated for effect size. Bonferroni correction was applied for multiple comparisons. Spearman correlation was used to examine the correlation among serum lipid fractions and clinical profile of the study group.

RESULTS

Sample characteristics

Table 1 shows the comparison of socio-demographic variables between the patients of OCD and HC. There is no significant difference between the two groups in their socio-demographic characteristics. Table 2 shows the descriptive statistics of the clinical profile of OCD patients.

Comparison of serum lipids between OCD HC

There was statistically significant difference in serum lipids between groups, $F(7, 71) = 14.75$, $P < 0.001$;

Table 1: Comparison of Sociodemographic characteristics between OCD cases and healthy controls (HC)

	Variables	OCD (*n*=40) *n* (%)/Mean±SD	HC (*n*=40) *n* (%)/Mean±SD	*t*/*U*/χ^2	df/*Z*	*P*
Age (in years)		32.78±8.45	31.58±8.53	0.63	78	0.52
Education (years)		12.90±2.59	12.90±2.59	800.00^U	0.00^Z	1.00
Sex	Male	17 (21.3%)	24 (30.0%)	2.45	1	0.17
	Female	23 (28.7%)	16 (20.0%)			
Religion	Hindu	35 (43.8%)	33 (41.3%)	0.39	1	0.75
	Others	5 (6.3%)	7 (8.8%)			
Occupation	Employed	12 (15.0%)	12 (15.0%)	0.00	1	1.00
	Unemployed	28 (35.0%)	28 (35.0%)			
Marital Status	Married	33 (41.25%)	24 (30%)	3.94	1	0.06
	Unmarried	7 (8.75%)	16 (20%)			
Family Type	Nuclear	15 (18.75%)	17 (21.25%)	0.20	1	0.82
	Joint/Extended	25 (31.25%)	23 (28.75%)			
Habitat	Rural	17 (21.25%)	15 (18.75%)	0.20	1	0.82
	Urban	23 (28.75%)	25 (31.25%)			
Family History of Psychiatric Illness	Yes	8 (10%)	11 (13.75%)	0.62	1	0.60
	No	32 (40%)	29 (36.25%)			
Family History of Medical Illness	Yes	8 (10%)	6 (7.5%)	0.34	1	0.77
	No	32 (40%)	34 (42.5%)			

OCD=obsessive compulsive disorder, HC=healthy control, U=Mann-Whitney U, χ^2=Chi square, df=degree of freedom, SD=standard deviation

Table 2: Clinical characteristics of OCD Cases

Variables	OCD (*n*=40) Mean±SD	Minimum	Maximum	Range
Age of onset (years)	28.63±7.29	14.00	49.00	35.00
Duration of illness (years)	4.45±4.84	0.10	25.00	24.90
HDRS	14.23±3.93	6.00	22.00	16.00
HAM A	11.80±5.33	3.00	24.00	21.00
Y-BOCS Obsession	14.60±1.98	12.00	18.00	6.00
Y-BOCS Compulsion	14.68±3.42	5.00	19.00	14.00
Y BOCS TOTAL	29.03±3.61	12.00	35.00	23.00
BIS Attention	12.38±3.09	8.00	23.00	15.00
BIS Motor	21.20±7.47	10.00	38.00	28.00
BIS Non-Planning	21.05±7.50	10.00	39.00	29.00
BISTotal	54.73±17.06	28.00	92.00	64.00

HDRS=Hamilton depression rating scale, HAM-A=Hamilton anxiety rating scale, Y BOCS=Yale brown obsessive-compulsive scale, BIS=Barratt's Impulsiveness scale-11

Wilk's Δ=0.40, partial η^2 = 0.59. Table 3 shows significant difference for serum HDL and serum apolipoprotein B between the groups. Table 4 shows statistically significant difference between the groups for serum HDL (P < 0.001, partial η^2 = 0.176) and apolipoprotein B (P < 0.001, partial η^2=0.53).

Comparisons between OCD patients with high and low impulsivity (Median = 49.50)

With median split analysis, patients with OCD were classified as OCD with high impulsivity and OCD with low impulsivity. No significant difference was observed between these groups, F (7, 31)=0.96, P = 0.47; Wilk's Δ=0.82, partial η^2 = 0.17). Further analysis did not reveal any significant difference for serum lipid fractions between these groups. Tables 5 and 6 show between-subject effects and the comparisons.

Correlations among variables in patients of OCD

The findings suggest a significant negative correlation of Y-BOCS compulsion score with serum TG (r_s =-0.34, P = 0.03) and apolipoprotein B (r_s = -0.32, P = 0.04) levels. Y-BOCS total score negatively correlated with serum TG (r_s = -0.45, P < 0.01) and serum VLDL (r_s = -0.39, P = 0.01). Serum HDL levels negatively correlated with BI Sattention (r_s = -0.32, P = 0.03), BIS motor (r_s = -0.40, P = 0.01), and BIS non-planning (r_s = -0.36, P = 0.02), and BIS total (r_s = -0.36, P = 0.01). Additionally, BIS motor positively correlated with serum VLDL levels (r_s = 0.34, P = 0.03). Table 7 shows correlations among serum lipid fractions and clinical profile of OCD cases.

DISCUSSION

Socio-demographic characteristics

In the present study, the mean age of patients with OCD and control groups was 32.78 ± 8.45 years and 31.58 ± 8.53 years, respectively. Both cases and control groups are comparable in terms of age, with no statistically significant difference (P = 0.52). The mean duration of the education of patients with OCD was 12.90 ± 2.59 years. These are consistent with the findings of a recent multicentric study on gender differences in OCD.[28]

Our OCD group had more females than males. This was unlike a few studies where OCD has an approximately equal male and female gender[29,30] or the males had more representation.[28] Awareness about mental illnesses has increased, which probably brings more females to treatment than before. There

Table 3: Test of between subject effects (*n*=80)

	Type III Sum of Squares	df	Mean Square	*F*	*P*	Partial η^2
Serum Cholesterol	3686.86	1	3686.86	3.57	0.06	0.044
Serum HDL	1682.37	1	1682.37	16.44	<0.001***	0.176
Serum LDL	940.14	1	940.14	1.82	0.18	0.023
Serum TG	310.22	1	310.22	0.15	0.69	0.002
Serum VLDL	139.92	1	139.92	0.42	0.51	0.006
Serum Apolipoprotein A1	48.40	1	48.40	0.86	0.35	0.011
Serum Apolipoprotein B	2952.26	1	2952.26	87.34	<0.001***	0.531

HDL=High density lipoproteins, LDL=Low density lipoproteins, TG=Triglycerides, VLDL=Very low-density lipoproteins, ***$P<0.001$

Table 4: Comparison of Serum Lipids between OCD Cases and Healthy Controls (*n*=80)

Serum Lipids	Group (*n*=40)	Mean±SD	95% Confidence Interval		P^a	Partial η^2
			Lower Bound	Upper Bound		
Serum Cholesterol	OCD	154.98±30.95	144.18	164.42	0.06	0.044
	HC	167.52±33.72	157.80	178.03		
Serum HDL	OCD	45.65±11.59	42.52	48.89	<0.001***	0.176
	HC	36.57±8.30	33.32	39.70		
Serum LDL	OCD	80.10±25.04	72.90	87.22	0.18	0.023
	HC	86.90±19.81	79.77	94.09		
Serum TG	OCD	120.47±52.29	106.18	134.21	0.69	0.002
	HC	123.87±34.58	110.13	138.16		
Serum VLDL	OCD	27.58±19.36	21.81	33.21	0.51	0.006
	HC	30.10±16.51	24.46	35.86		
Serum Apolipoprotein A1	OCD	132.81±8.44	130.49	135.22	0.35	0.011
	HC	131.30±6.30	128.930	133.661		
Serum Apolipoprotein B	OCD	51.72±7.23	49.983	53.648	<0.001***	0.531
	HC	39.72±4.20	37.802	41.467		

HC=Healthy Control, HDL=High density lipoproteins, LDL=Low density lipoproteins, TG=Triglycerides, VLDL=Very low-density lipoproteins, ***$P<0.001$, [a]Adjusted for multiple comparison: Bonferroni

Table 5: Tests of Between-Subjects Effects (*n*=40)

	Type III sum of squares	df	Mean square	*F*	*P*	Partial η^2
Serum Cholesterol	0.60	1	0.60	0.00	0.98	0.000
Serum HDL	482.47	1	482.47	3.75	0.06	0.092
Serum LDL	490.93	1	490.93	0.78	0.38	0.021
Serum TG	8297.18	1	8297.18	3.17	0.08	0.079
Serum VLDL	848.78	1	848.78	2.30	0.13	0.059
Serum Apolipoprotein A1	103.66	1	103.66	1.43	0.23	0.037
Serum Apolipoprotein B	66.83	1	66.83	1.30	0.26	0.034

HDL=High density lipoproteins, LDL=Low density lipoproteins, TG=Triglycerides, VLDL=Very low-density lipoproteins, $P<0.05$

was no statistically significant difference between the two groups (P = 0.179), which suggests homogeneity between the cases and HC in the terms of gender.

The average age of onset of the illness of our patient group was 28.63 ± 7.29 years, which is in somewhat agreement with other studies.[28,31,32] The mean duration of illness in the study was 4.45 ± 4.84 years, which was shorter than that found in a recent multicentric study.[28] We found that the majority of the OCD patients were married. Most studies show that patients are reluctant to get married, perhaps due to their involvement in OC rituals, and between the genders, females with OCD are more likely to get married.[33,34] Tripathi *et al*.[28] had found that the majority of their sample and the majority of females in their sample were married. Thus, the higher female representation may explain our finding on marital status. Most of the patients with OCD were unemployed (35%). There are several lines of evidence suggesting that unemployment and decreased economic productivity may be associated with OCD.[35-38]The majority of the patients were Hindus (43.8%), which is consistent with a recent study[28] and is presumably due to the larger representation of Hindus in the general population.

Clinical profile of OCD cases

The symptom severity of OCD was high, as evidenced by the total Y-BOCS score being 29.03 ± 3.61, which suggests that the cases had severe disorder on an average, with an almost equal severity of obsessive and compulsive symptoms. For total impulsivity scores, higher values were seen in motor and non-planning impulsivity than in attentional.

Comparison of serum lipid profile between OCD cases and HC

We found that OCD patients have significantly higher HDL and serum apolipoprotein B levels than

Table 6: Comparison of Serum Lipids between high impulsivity OCD and low impulsivity OCD cases (*n*=40)

	Groups	Mean±SD	95% Confidence Interval		*P*[a]	Partial η^2
			Lower Bound	Upper Bound		
Serum Cholesterol	High impulsivity OCD	153.25±31.82	140.93	168.71	0.98	0.000
	Low impulsivity OCD	156.15±30.82	140.68	168.46		
Serum lipids-HDL	High impulsivity OCD	42.20±10.38	36.94	47.30	0.06	0.060
	Low impulsivity OCD	49.10±11.95	44.00	54.35		
Serum LDL	High impulsivity OCD	82.75±23.61	72.23	95.08	0.38	0.021
	Low impulsivity OCD	77.45±26.73	65.11	87.96		
Serum TG	High impulsivity OCD	133.55±52.78	111.74	158.46	0.08	0.079
	Low impulsivity OCD	107.40±49.66	82.48	129.20		
Serum VLDL	High impulsivity OCD	31.74±21.70	23.50	41.01	0.13	0.137
	Low impulsivity OCD	23.42±16.19	14.144	31.656		
Serum Apolipoprotein A1	High impulsivity OCD	131.3500±8.00181	127.334	135.094	0.23	0.037
	Low impulsivity OCD	134.3500±8.81551	130.606	138.366		
Serum Apolipoprotein B	High impulsivity OCD	50.7000±7.44877	47.142	53.682	0.26	0.034
	Low impulsivity OCD	52.7500±7.05523	49.768	56.308		

HDL=High density lipoproteins, LDL=Low density lipoproteins, TG=Triglycerides, VLDL=Very low-density lipoproteins, $P<0.05$, [a]Adjusted for multiple comparison: Bonferroni

Table 7: Spearman Correlations among OCD cases (*n*=40)

Variables		Serum TG	Serum Cholesterol	Serum HDL	Serum LDL	Serum VLDL	Serum Apolipoprtein A1	Serum Apolipoprotein B
Y-BOCS Obsession	r_s	-0.11	-0.22	-0.19	-0.05	-0.10	-0.09	0.08
	p	0.47	0.16	0.23	0.73	0.54	0.57	0.59
Y-BOCS Compulsion	r_s	-0.34*	0.02	0.17	0.01	-0.27	0.11	-0.32*
	p	0.03*	0.86	0.27	0.92	0.08	0.49	0.04*
Y-BOCS Total	r_s	-0.45**	-0.03	0.20	0.04	-0.39*	0.00	-0.26
	p	<0.01**	0.84	0.21	0.78	0.01*	0.98	0.09
HDRS	r_s	0.24	0.18	-0.04	0.07	0.18	-0.01	0.10
	p	0.12	0.26	0.78	0.63	0.25	0.93	0.52
HAM A	r_s	0.11	-0.02	-0.03	-0.11	0.10	-0.05	0.01
	p	0.47	0.88	0.80	0.47	0.52	0.75	0.90
BIS Attention	r_s	0.24	0.06	-0.32*	0.02	0.26	-0.04	-0.07
	p	0.12	0.70	0.03*	0.87	0.10	0.77	0.63
BIS Motor	r_s	0.29	0.02	-0.40**	0.14	0.34*	-0.23	-0.25
	p	0.06	0.90	0.01*	0.36	0.03*	0.13	0.10
BIS Non planning	r_s	0.25	-0.15	-0.36*	0.08	0.31	-0.15	-0.19
	p	0.11	0.33	0.02*	0.61	0.05	0.35	0.21
BIS Total	r_s	0.28	-0.07	-0.36*	0.11	0.33*	-0.20	-0.17
	p	0.07	0.65	0.01*	0.48	0.03*	0.21	0.27

*$P<0.05$, **$P<0.01$, rs=Spearman's correlation coefficient, HDRS=Hamilton depression rating scale, HAM A=Hamilton anxiety rating scale, Y-BOCS=Yale-Brown obsessive compulsive scale, BIS=Barratt's Impulsiveness scale-11, HDL=High density lipoproteins, LDL=Low density lipoproteins, TG=Triglycerides, VLDL=Very low density lipoproteins

healthy controls. Agargun *et al*.[39] revealed higher LDL, VLDL, and triglyceride levels, but lower HDL levels, than normal controls. Peter *et al*. noted similar findings.[40,41] Freedman *et al*.[42] found normal cholesterol levels in OCD. However, these findings are not consistent with the present study, which found higher serum HDL levels in the OCD group than in normal controls, along with other lipid fractions being similar between the two groups. A possible explanation for the contradictory findings in the present study might be the small size and other characteristics of our sample.

Regarding the role of serum apolipoproteins and human behaviors, much data do not exist. However, low apo B levels are seen in Indian males with a history of violent crimes compared to controls.[43] Kavoor *et al*.[21] showed a significant negative correlation between serum apo B levels and impulsivity in bipolar patients. But no study investigating the serum apolipoproteins in OCD patients has been done so far. The present study found statistically significant higher values of serum apolipoprotein B in the OCD group than HC. Whether this is related to the disease process of OCD or its specific characteristics needs to be further examined.

Comparison between high impulsivity and low impulsivity OCD patients

Our study did not find any difference in serum lipids between OCD with high or low impulsivity. A trend toward lower serum HDL ($P = 0.06$, partial $\eta^2 = 0.06$) was observed in OCD with high impulsivity group. Similar findings were associated with higher suicidal behavior, which can be attributed to high impulsivity in drug naïve patients of OCD.[44] Aguglia *et al*.[45] also found low serum HDL along with low serum triglycerides in patients of OCD having high impulsivity as manifested by their self-harming behaviors than normal controls. Several researchers have studied the role of low serum HDL cholesterol in impulsive behaviors.[17,46,47] They believe that HDL is the most important lipid fraction when considering impulsivity as a whole. Our study also has indicated this trend. Moreover, several studies have shown that OCD patients may have increased oxidative stress and that this correlates with disease severity; we may speculate that lipid peroxidation might be one of the causes of reduced serum HDL-C and altered lipid profile in these patients.[48,49] A trend towards higher serum VLDL was observed among OCD cases than HC,which is similar to an earlier study.[39]

Correlations between OCD clinical profile and serum lipid profile

We found significant negative correlations among serum TG, apolipoprotein B, and Y-BOCS compulsion scores. Y-BOCS total score was significantly negatively correlated with serum TG and serum VLDL. Serum HDL levels of OCD patients were negatively correlated with BIS total, BIS attention, BIS motor, and BIS non-planning. Additionally, BIS motor was positively correlated with serum VLDL. A previous study[39] showed lower serum HDL in a sample of OCD patients thanHC. These findings are in line with a few other studies.[40,41] But in none of these studies, the correlation among illness severity, impulsivity, and serum lipids were examined. The present results are not in concurrence with these studies, and as enough data between the correlation of individual scores on Y-BOCS and serum lipid fractions do not exist, this requires further research.

We found a statistically significant negative correlation between serum HDL levels and BIS total, BIS attention, BIS motor, and BIS non-planning. De Berardis *et al*.[44] and Aguglia *et al*.[45] had demonstrated low HDL levels associated with higher suicidal ideation, which is a measure of higher attentional impulsivity in drug naïve patients of OCD, but a correlation was not established between impulsivity and serum HDL levels. Kavoor *et al*.[21] revealed a statistically significant negative correlation between impulsivity and serum lipid fractions, namely total cholesterol and triglycerides, but not serum HDL in bipolar patients. Our findings are in contrast to the results of another recent study among the patients of schizophrenia where total cholesterol and LDL levels showed significant negative correlations with scores on impulsivity ($P < 0.01$) and serum TG level showed a negative correlation with impulsivity ($P < 0.05$).[20]

Limitations and future directions

Our study adds to the growing literature on the complex relationship among lipid fractions, impulsivity, and psychiatric disorders. But it suffers from some limitations. The sample size was small. Physical factors influencing serum lipids were not assessed. Tool to measure impulsivity was self-report measure without adaptation. Impulsivity was not assessed in the HC group. Future research including a larger sample size and metabolic profile should be conducted.

CONCLUSION

There is a significant statistical difference in serum HDL and serum apolipoprotein B between drug naïve patients of OCD and age- and sex-matched HC. Serum HDL was negatively correlated with all scores of impulsivities. Serum TG and apolipoprotein B were negatively correlated with the Y-BOCS compulsion score. Serum TG and serum VLDL were negatively corelated with Y-BOCS total score, whereas only serum VLDL was positively correlated BIS motor scores.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Emotion Dysregulation and Early Trauma in Borderline Personality Disorder: An Exploratory Study

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ABSTRACT

Background: Borderline personality disorder (BPD) research is in its nascent stage in India though studies have estimated its prevalence in psychiatric conditions. Trauma experiences and emotion regulation difficulties are well documented in BPD in the international literature. Thus, it is imperative to examine the role of trauma experiences and their relation to emotion dysregulation in BPD in the Indian context. **Materials and Methods:** This study used both self-report and semistructured interview data from 34 adults with BPD who presented for outpatient or inpatient psychiatric treatment and compared them with a gender-matched control group. The tools used were the International Personality Disorder Examination, Kessler-10, Early Trauma Inventory Self Report-Short Form, modified-Positive And Negative Affect Scale, Cognitive Emotion Regulation Questionnaire, and Difficulties in Emotion Regulation Scale (DERS). **Results:** The BPD group reported higher negative affect, increased use of maladaptive emotion regulation strategies and a deficit of adaptive strategies, after depression scores were controlled for. General abuse, physical punishment, and emotional abuse were significantly higher in the BPD group. The high occurrence of childhood emotional abuse and negative affect in BPD patients emerged as a major correlate accounting for 68.4% of the variance in DERS scores. **Conclusions:** Although we obtained results similar to the western literature on BPD pathology, sociocultural factors such as family and economic conditions, cultural differences in symptom expression of BPD, and treatment forms used in India warrant further research.

Key words: *Borderline personality, culture, early trauma, emotion dysregulation, emotional abuse*

Key messages: *1. Higher levels of childhood emotional abuse lead to severe emotion dysregulation. 2. BPD group experiences higher negative affect, use greater maladaptive strategies and report a deficit of adaptive strategies. 3. Socioeconomic factors, cultural differences in symptom expression and treatment of BPD in India warrant further research.*

Borderline personality disorder (BPD) is present in 1–3% of the general population. Clinically, it is the

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most commonly diagnosed personality disorder, present in 10% of patients in outpatient settings, 15–20% of patients in inpatient settings, and 30–60% of patients diagnosed with personality disorders (PDs).[1,2] In the Asian subcontinent, especially in India, there are few studies on the prevalence of BPD and they have methodological limitations. Thus, the prevalence is inconsistent and unclear (0.6–1% or even higher).[3,4]

The first clinical study in Asia on BPD was carried out in Japan (1993) and involved 85 female outpatients aged 18–30 years. The clinical picture was similar to the West, except for a low co-morbidity with substance use disorders, and stormy relationships with the family rather than the romantic partners.[5] This is relevant to the context in Asia, which has a collectivist culture and most individuals have deep ties with families and live with them during the early adulthood.

It can be said with some certainty that BPD is common in the Indian subcontinent,[3-5] with a high prevalence of psychiatric and personality comorbidity.[6,7] Studies have estimated high rates of BPD in Axis-1 conditions such as eating disorders,[8] deliberate self-harm,[9] attempting suicide,[10,11] internet addiction,[12] and substance use disorders.[13] Because most patients seek treatment for co-morbid Axis-1 issues, the distress stemming from BPD may not be addressed, thereby compromising the quality of care and a complete recovery from the clinical symptoms.

Traumatic separation from one or both parents, or loss of parental figures during childhood are etiologically relevant in almost 20–40% of individuals with BPD.[14] A high percentage of individuals with BPD report a history of neglect (92%), physical abuse (25%–73%), or sexual abuse (40%–76%) within the family context.[15] In a study conducted at Massachusetts, child sexual abuse was reported in more than 50% in those with BPD, and the severity of the abuse was significantly related to the BPD severity and psychosocial impairment.[16] Some studies report that, along with sexual abuse, emotional abuse and neglect are also associated with symptoms of BPD.[17,18] Other studies have found that emotional abuse is the only form of maltreatment that had an association with BPD above and beyond other forms of abuse and neglect.[19,20] In most studies, emotional and (or) sexual abuse are associated with the severity of BPD symptoms. These inconsistent findings could be due to the use of self-report questionnaires or an inclusion of all PDs. Thus, in the development of BPD, abuse is seen as a central etiological variable and a critical risk factor.[21]

In those with BPD, a symptom requiring immediate clinical attention, after self-harm, is emotion dysregulation.[22-24] These patients have difficulties in recognizing and labeling their own emotions and in employing emotion regulation strategies.[23,25] Negative affect and emotion dysregulation are highly correlated in BPD.[26] In order to reduce the negative affect, they may employ maladaptive cognitive strategies such as rumination[27,28] and thought suppression,[29] which often increase, rather than decrease, the negative affect. Individuals with BPD avoid potentially distressing situations[29-32] and have low distress tolerance,[21] which contributes further to emotion dysregulation.

The available literature compares individuals with BPD with diverse control groups (e.g., patients with depression or other personality disorders, or mixed samples of psychiatric patients).[33,34] One of the concerns in comparing such groups would be the difficulty in establishing the absence of emotion dysregulation in the comorbid Axis-I disorders such as depression and anxiety disorders.

Therefore, the overall objectives of this study were to explore the nature of early trauma experiences and its relation to emotion regulation in individuals with BPD and to examine the correlates of the severity of emotion dysregulation. This would help in understanding culturally relevant aspects of BPD pathology in India and provide future directions with respect to BPD research.

MATERIALS AND METHODS

Individuals with BPD presenting for outpatient or inpatient psychiatric care, to the Department of Psychiatry, National Institute of Mental Health And Neurosciences (NIMHANS), Bengaluru between August 2015 to February 2016 were recruited. The institute is the largest training center for mental health and neuroscience professionals in the country. It provides post-graduate training and imparts advanced technical knowledge to medical, para-medical, and nursing professionals.

G*Power software version 3.1.9.4 was used to estimate the sample size for cross-sectional exploratory study design, based on the data from a pilot phase (n = 10). The α level was set at 0.05, with a power of 0.95 and an effect size of 0.9. The sample size was estimated to be 34 in each group (study and control).

Participants were selected into the BPD group after establishing the diagnosis. Individuals with a diagnosis of BPD given by a psychiatrist after evaluation were included. In addition, international personality disorder examination (IPDE) was also done by the researcher to corroborate the diagnosis. The control

group was selected, using convenience sampling, from acquaintances residing around the hospital.

Participants in both the BPD and control groups were interviewed by the investigator AJ using IPDE[35] to establish a diagnosis of BPD. The inclusion criteria for both groups were age 18–35 years, educated up to Class X, and a working knowledge of English. Participants with a history of developmental disabilities or difficulty communicating in English were excluded. Participants in the control group were excluded if they met criteria for any PD on IPDE and/or scored above the cut-off (20 and above) either on the Kessler-10 (K-10, a 10 item screening questionnaire)[36] or above 13 on Beck's Depression Inventory-II (BDI-II), to ensure that they had no Axis-1 disorders.

Tools used

All the tools were administered in English. In both the groups, various dimensions of emotion dysregulation were assessed using self-report tools. These tools have been used primarily with psychiatric population and also used with normal populations.

Modified positive and negative affect schedule (m-PANAS)[37] assessed current levels of positive and negative affect by rating the degree to which they experienced a particular mood descriptor on a 5-point scale. Cronbach's alpha coefficients for the happiness, sadness, and anger subscales were .90, .80, and .74.

The difficulties in emotion regulation scale (DERS, a brief, 36-item, self-report questionnaire) assessed six aspects of emotion dysregulation (derived through factor analysis). As for the test-retest reliability, 194 subjects completed the test and 21 agreed to complete DERS between weeks 4 and 8. The correlation coefficient on total DERS was. 88 with an internal consistency of. 93 (DERS total). Only the overall score was taken for the analyses.

The cognitive emotion regulation questionnaire-short (CERQ), an 18-item multidimensional questionnaire, identified the cognitive emotion regulation strategies (or cognitive coping strategies) one uses after having experienced negative events. It has nine conceptual scales, grouped into maladaptive strategies (other-blame, rumination, catastrophizing, and self-blame; higher scores on this indicates greater use) and adaptive strategies (positive refocusing, planning, positive reappraisal, putting into perspective, and acceptance; lower score indicates lesser use). Reliability alpha coefficients for the subscales had ranged from. 67 to. 81.[38]

Early trauma inventory self report-short form (ETISR-SF),[39] a 27-item semistructured interview, assessed the four domains of physical, emotional or sexual abuse, and general traumatic experience, and then, in an additional question, explored the most serious trauma before the age of 18 years. This was used as a predictor variable in the current study. All domains showed high internal consistency (Cronbach coefficient $\alpha > 0.7$).

Beck's depression inventory-II (BDI-II, a four-point rating scale) looked at the current level of depression, and the scores were controlled for in the regression analyses. Reliability coefficients range from. 90 to. 95.[40]

The study protocol was reviewed and approved by the Institute Ethics Review Board. Both the groups provided informed, written consent to participate.

For the study group, 50 participants with a case file diagnosis of BPD and seeking treatment at the inpatient or outpatient departments were approached for the study. Out of the 50, 4 did not meet the IPDE criteria for BPD, 13 did not consent to participate in the study, and finally, 33 participants were recruited for the study. One participant from the control group met criteria for BPD and was included, to reach a final number of 34.

For the control group, 43 participants matched by gender were approached. Following a debriefing session, one participant refused consent. One participant reported obsessive compulsive symptoms that were diagnosable after a semistructured interview; four participants had high scores (>20) on K-10, and two participants had moderate depression (BDI-II score >25). Only when psychological distress or depression was not detected on these tools, they were given further assessments, i.e. m-PANAS, CERQ, ETISR-SF, and DERS.

All analyses were carried out using IBM Statistical Package for Social Sciences for Windows, Version 20.0. Shapiro Wilk's test was used to check for normality of data. Most of the data did not follow a normal distribution. Therefore, nonparametric analyses were carried out. Fisher's exact test (for categorical data) and Mann–Whitney's *U* test (for continuous data) were used to compare between-group (i.e., BPD and control group) differences in sociodemographic data, early trauma experiences, and emotion regulation. Binary logistic regression was carried out to look for variables predictive of emotion regulation.

RESULTS

Demographic characteristics of BPD and control groups can be found in Table 1.

Table 1: Comparison of sociodemographic data between BPD and control groups using Fisher's exact test

Sample characteristics	BPD Median=23.50 (IQR=7)		Control group Median=26.00 (IQR=6)		Fisher's exact, *P*
	n	%	*n*	%	
Age					
Education					
High school	10	29.4	2	5.9	*P*=0.597†
Graduate	17	50.0	10	29.4	
Postgraduate/above	7	20.6	22	64.7	
Socioeconomic Status					
Low	3	8.8	1	2.9	*P*=1.00†
Middle	30	88.2	32	94.1	
High	1	2.9	1	2.9	
Marital Status					
Single	21	61.8	18	52.9	*P*=0.038**
Married	9	26.5	15	44.1	
Separated/Divorced	4	11.8	1	2.9	
Family history of psychiatric illness					
Present	24	70.6	9	26.5	*P*=0.395†
Absent	10	29.4	25	73.5	

*Significant at 0.01 level, **significant at 0.05 level, †not significant, IQR – interquartile range, BPD – Borderline Personality Disorder, *n* – Total number of cases, % – Percentage of cases

The study group was predominantly in the age group of 18–23 years (50%). The overall representation of gender was 24 females and ten males in each of the groups. The minimum age was 18 years, and the maximum was 31 years. The mean duration of illness (±SD) was 4.82 (±2.44) years, with minimum and maximum duration ranging from 1 to 10 years for both BPD and the related co-morbid conditions. The control group had a higher proportion of postgraduates in comparison to the BPD group, which had more graduates. Participants from both the groups belonged mostly to the middle socioeconomic status. Majority in the BPD group were single. The BPD group had a higher proportion of family history of psychiatric illness as compared to the control group.

More than two-thirds of them in the BPD group were on medication and had a comorbid psychiatric diagnosis, and about one-third of them had an independent diagnosis of BPD (26.5%). The diagnosis was arrived at after a detailed workup by trainees and supervised by a senior resident/junior consultant. The final diagnosis was arrived at after consultation with a psychiatrist. The Axis-1 diagnoses were documented from the case files, and depression was found to be the most frequent co-morbidity (23.5%) followed by OCD, other personality disorders, ADHD, and adjustment disorder.

BPD group had significantly higher levels of negative affect, lower levels of positive affect, severe emotion dysregulation, and excessive use of maladaptive emotion regulation strategies such as rumination, catastrophization, and other-blame along with poor use of adaptive strategies for emotion regulation [Table 2].

Except for the sexual abuse subscale, both the groups differed significantly on general abuse, emotional abuse, physical punishment, and global subscales of ETISR-SF. The BPD group had higher median scores [Table 3].

Difficulties in emotion regulation and negative affect are positively correlated with general trauma, physical abuse, and emotional abuse. Difficulties in emotion regulation have a strong positive correlation with emotional abuse, whereas the rest of the variables have a moderate correlation among each other. This implies that when the emotional, physical, or general abuse increases, there would be a corresponding increase in the difficulties in emotion regulation.

To test for multicollinearity, intercorrelations between the predictor variables were examined. None of the predictor variables had a variance inflation factor greater than 0.65, indicating no serious multicollinearity among the variables. Significant positive correlations with DERS were found on subscales of ETISR-SF—general trauma, emotional abuse, and physical punishment along with negative affect subscale of m-PANAS [Table 4].

Binary logistic regression was applied [Table 5]. The outcome variable, DERS scores, was coded as individuals having either low or high emotion dysregulation (1 = high, 0 = low) on the basis of the median of the entire sample. The DERS scores for the combined group ranged from 40 to 164, with a median of 94 and IQR of 57. A five-predictor logistic model (negative affect, general trauma, physical punishment, emotional abuse, and sexual abuse) was fitted to the data to test the research hypothesis "the likelihood that an individual develops emotion dysregulation is related to his/her scores on negative affect, general trauma, physical punishment, emotional abuse, and sexual abuse". General trauma, physical punishment, and sexual abuse subscales scores of ETISR-SF got excluded, and the remaining two variables produced Nagelkerke $R^2 = 0.684$ and accounted for 68.4% of the variance in DERS scores [Table 6].

A highly significant overall effect was found on the mPANAS negative affect scale (Wald = 10.334, df = 1, P =0.001) and the Emotional Abuse subscale of ETISR-SF (Wald = 8.57, df = 1, P = 0.003). The β coefficient was significant and positive for

Table 2: Emotion dysregulation scores in BPD and control groups

Emotion dysregulation	BPD (*n*=34)		Control group (*n*=34)		Mann-Whitney U test
	Mdn	IQR	Mdn	IQR	Sig. level (2-tailed)
Difficulties in Emotion Regulation Scale (DERS)	128.50	30.00	73	24	*U*=28.00, *P*=0.001*
Subscales of Cognitive Emotion Regulation Questionnaire (CERQ)					
Rumination	7.00	4.00	5.00	2.00	*U*=318.00, *P*=0.001*
Self-Blame	5.00	5.00	4.00	2.00	*U*=521.50, *P*=0.487†
Catastrophization	8.00	4.00	4.00	2.00	*U*=150.00, *P*=0.001*
Other-Blame	6.00	5.00	4.00	2.00	*U*=339.00, *P*=0.002*
Maladaptive Strategies Total	26.50	10.00	16.50	7.00	*U*=174.50, *P*<0.001*
Adaptive Strategies Total	27.00	10.00	30.00	13.00	*U*=402.50, *P*=0.031**
m-PANAS-positive affect scale	24.00	14.00	39.00	8.00	*U*=155.00, *P*<0.001*
m-PANAS- negative affect scale	34.00	15.00	16.00	10.00	*U*=142.50, *P*<0.001*

*Significant at 0.01 level, **significant at 0.05 level, †not significant, BPD – Borderline personality disorder (study group), Mdn – Median, IQR – Interquartile range, m-PANAS – Modified positive and negative affect schedule

Table 3: Early trauma experiences in BPD and control groups

Early traumatic experiences	BPD (*n*=34)		Control Group (*n*=34)		Mann-Whitney U test
	Mdn	IQR	Mdn	IQR	*u*/sig. (2-tailed)
ETISR-SF					
General Trauma	3.00	3.00	1.00	2.00	*U*=254.50, *P*<0.001*
Physical Punishment	3.00	2.00	0.00	1.00	*U*=138.00, *P*<0.001*
Emotional Abuse	4.00	2.00	0.00	2.00	*U*=100.50, *P*<0.001*
Sexual Abuse	0.00	2.00	0.00	0.00	*U*=453.00, *P*=0.062†
Total	11.00	6.00	3.00	4.00	*U*=86.50, *P*<0.001*

*Significant at 0.01 level, **significant at 0.05 level, †not significant, BPD – Borderline Personality Disorder (study group), Mdn – Median, IQR – Interquartile range, U – Mann-Whitney's U test value, ETISR-SF – Early trauma inventory self report-short form

Table 4: Spearman's rank correlation coefficient (Rho) between subscales of ETISR-SF, m-PANAS, and DERS

	DERS	PANASn	ETISRGT	ETISRPP	ETISREA	ETISRSE
DERS	1	0.68**	0.42**	0.59**	0.69**	0.18
PANAS negative affect scale		1	0.33**	0.41**	0.44**	0.15
ETISR-GT			1	0.47**	0.49**	0.24*
ETISR-PP				1	0.64**	0.33
ETISR-EA					1	0.36*
ETISR-SE						1

DERS – Difficulties in emotion regulation, PANASn – Negative affect, ETISR-GT – General trauma, ETISR-PP – Physical abuse, ETISR-EA – Emotional abuse, ETISR-SE – Sexual abuse, ETISR-SF – Early trauma inventory self report-short form. **Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed)

both, indicating that an increase in negative affect (OR = 1.161, P = 0.001, 95% CI 1.06, 1.271) and emotional abuse (OR = 2.339, P = .003, 95% CI 1.324, 4.132) is associated with increased odds of emotion dysregulation. There was no significant overall effect on general trauma (Wald = 0.023, df = 1, P = 0.880), physical punishment (Wald = 0.004, df = 1, P = 0.952), or sexual subscales of ETISR-SF (Wald = 0.041, df = 1, P = 0.840).

The model with the variables correctly classifies the outcome for 83.8% of the cases, compared to 51.5% in the null model. The model summary shows the -2LL (45.258), which is compared to the -2LL for the null model in the omnibus test of model coefficients and is highly significant (χ^2 = 48.951, df = 5, P < 0.001); therefore, our new model is significantly better. The Nagelkerke's R^2 suggests that the model explains roughly 68.4% of the variance in DERS scores. Hosmer and Lemeshow test of the goodness of fit suggests the model is a good fit to the data as P = 0.753 (>0.05).

DISCUSSION

More than two-thirds of the BPD patients had a family history of psychiatric illness, whereas only a small number of the control group had such history. Prevalence of psychiatric illness in the family is almost double the numbers as found in the Western literature.[41] The findings throw light on the fact that there is a high prevalence of psychiatric illness in the families of individuals with BPD. Some Asian studies[3,42] have reported the negative impact of family psychopathology on BPD.

More than two-thirds of the BPD group was on medication for co-morbid conditions. Majority of the participants had an independent diagnosis of BPD with no co-morbidity. The highest co-morbidity was depression, followed by OCD, other personality disorders, and other disorders. The average duration of illness reported by the BPD group was about 4 years, and seeking treatment for PDs is generally delayed as most seek treatment when Axis-I symptoms manifest. According to the National Collaborating Center for Mental Health,[43] the exacerbation of BPD symptoms overlaps with co-morbid conditions and its course fluctuates with depressive, schizophrenic, impulsive, dissociative, and identity disorders. Hence, a related co-morbid condition makes it difficult to determine

Table 5: Binary logistic regression analysis using DERS as outcome variable

Predictor	β	SE β	Wald's χ^2	df	*P*	Odds ratio (OR)	95% C.I. for OR	
							Lower	Upper
Constant	−5.267	1.334	15.594	1	0.001	NA	NA	NA
Negative affect	0.149	0.046	10.334	1	0.001**	1.161	1.060	1.271
General trauma	0.045	0.295	0.023	1	0.880	1.046	0.587	1.862
Physical Punishment	0.019	0.308	0.004	1	0.952	1.019	0.557	1.864
Emotional Abuse	0.850	0.290	8.572	1	0.003**	2.339	1.324	4.132
Sexual Abuse	0.073	0.360	0.041	1	0.840	1.075	0.531	2.177

DERS – Difficulties in emotion regulation, df – Degrees of freedom, OR – Odds Ratio, C.I. – Confidence Interval. ** Correlation is significant at the 0.01 level (2-tailed)

Table 6: Classification table of the null model and model along with variables

Null model					Model with variables			
Emotion Dysregulation	Observed	Predicted DERS		Percentage correct	Observed	Predicted DERS		Percentage correct
		Low	High			Low	High	
	Low (0)	0	33	0.0	Low (0)	28	5	84.8
	High (1)	0	35	100.0	High (1)	6	29	82.9
Overall Percentage				51.5	Overall Percentage			83.8

Model summary		Goodness-of-fit test	χ^2	*df*	*P*
-2 Log likelihood	45.258[a]		5.046	8	0.753
Cox & Snell R^2	0.513	Omnibus test of coefficients	48.951	5	<0.001**
Nagelkerke R^2	0.684**				

DERS – Difficulties in emotion regulation, df – Degrees of freedom. **Correlation is significant at the 0.01 level (2-tailed)

if the presenting symptoms are those of BPD. Nath *et al.*[9] similarly found that only 5% of the young adults presenting with deliberate self-harm had more than one personality disorder diagnosis, in light of the high prevalence of personality disorders in a part of the Asian subcontinent. However, comorbidity of PTSD in the current sample was not as common as reported in the western literature.[44] This could be because there might have been traumatic events where treatment was not sought; however, this needs further exploration. Research has also found that PTSD does not cease to be diagnosed and is frequently associated with higher levels of sexual abuse,[45] which is not statistically significant in the current sample.

Emotion dysregulation was found to distinguish those with BPD from the control group. Scores on DERS were almost double of that found in the control group. As hypothesized in several models of BPD, support for the findings come from BPD[46] and depressive psychopathology,[47] where both BPD patients and major depressive disorder patients reported clinically relevant difficulties in emotion regulation. The literature suggests that those who have BPD have intense negative responses to everyday life events have trait-negative affect[48] and experience more negative affect.[49,50] Some individuals employ cognitive strategies to overcome the negative affect, thereby regulating their emotions cognitively. These strategies could be both adaptive and maladaptive. Specifically, the current sample used rumination, catastrophization, other-blame, and self-blame as strategies to overcome distress. Rumination and thought suppression have been found to be used more frequently by other BPD samples as well. These findings throw light on the specific strategies that maintain and exacerbate emotion dysregulation.[51,52]

The high occurrence of childhood emotional abuse in BPD patients is consistent with prior results.[17,53] Similar results have been found in Asian studies with a nonclinical sample[54] and high-risk populations.[55] It can be speculated that emotional abuse and neglect may affect core processes of emotion regulation development and, therefore, have detrimental effects on emotion regulation over and above other forms of childhood adversities. The current study has found similar results regarding the difference between the BPD group and the control group, with the emotional abuse, physical abuse, and general trauma subscale of ETISR-SF being statistically significant [Table 3].

However, the difference between the BPD group and control group on the sexual events subscale of ETISR-SF was not significant unlike other studies.[16,24] Emotional abuse has emerged as a major predictor of emotion dysregulation in this sample. This finding is supported by previous studies. However, in this sample, sexual abuse experiences do not significantly differ from the control group, unlike the findings from the West[16] or

East[56] where emotion dysregulation has been explained by the negative effects of child sexual abuse.[57] This could be due to our use of a tool that addresses different kinds of abuse and difficulty in revealing a history of sexual abuse without adequate rapport and trust in the researcher. Nevertheless, many studies have underscored the fact that any form of abuse, especially sexual and emotional abuse overall, are found in those who have BPD, along with the fact that abuse and neglect are predictors of severity of BPD symptoms.[16,58]

Correlation and regression analyses [Tables 4-6] showed that DERS scores had a strong positive correlation with emotional abuse subscale of ETISR-SF, whereas the rest of the variables had a moderate correlation among each other [Table 5]. Studies examining the associations between various forms of maltreatment and BPD in adults have found that emotional abuse is the only form of maltreatment that has an association with BPD above and beyond other forms of abuse and neglect.[59] Sexual abuse was not significantly correlated with DERS in the current sample, unlike in literature where sexual abuse is one of the predictors for BPD.[17,58]

In the binary logistic regression analysis, negative affect and emotional abuse had significant positive regression weights, indicating that participants with higher scores on these are expected to have greater difficulties in emotion regulation. Some investigators[16] have presented good evidence that a high percentage of individuals with BPD report a history of neglect, physical abuse, and sexual abuse. Sexual abuse is often underreported in BPD, and especially in the Indian context, talking about sex or sexual abuse is a taboo. This could be one reason why there is underrepresentation of sexual abuse.[60]

According to the model, the log of the odds of an individual having emotion dysregulation was significantly and positively related to negative affect and emotional abuse. In other words, the higher the negative affect and emotional abuse, the more likely it is that an individual develops risk for emotion dysregulation. Those who have higher levels of negative affect were 1.16 times more likely than those who have lower levels of negative affect to emotionally dysregulate. For every one-unit increase in negative affect, the risk of emotion dysregulation increases by 16%. Those who have higher levels of emotional abuse were 2.33 times more likely than those who have lower levels of emotional abuse to emotionally dysregulate. For every one-unit increase in emotional abuse, the risk of emotion dysregulation increases by 133%. Compared to the null model, the model with variables explained more of the variance in the outcome and was highly significant. The model explains roughly 68.4% of the variance in DERS scores. Hosmer and Lemeshow test of the goodness of fit suggests that the model is a good fit to the data [Table 6].

This study highlights the necessity of treatment strategies for long-term maladaptation related to childhood trauma. It also elucidates the precise emotion regulation deficits that are central to BPD and would help sharpen the focus in therapy. It also indicates the risk of developing emotion dysregulation when one has a high negative affect or is exposed to emotional abuse.

This study has a few limitations; hence, our results need to be regarded as preliminary. First, we cannot rule out the possibility of response bias and the limits of self-reporting emotion regulation. Second, the cross-sectional design did not permit to test causal effects. Third, the use of convenience sampling may have led to selection bias, limiting the generalizability of this study. Finally, logistic regression models, which use categorical data, can appear to have more predictive power than they actually have, as a result of sampling bias. Hence, a larger sample and use of linear models with continuous data would predict results more accurately.

Future research should assess early/adult trauma experiences more comprehensively, including thorough clinical interviews, to examine additional trauma characteristics, such as the onset of childhood maltreatment, that might have a particular impact on emotion regulation. Further research on developing appropriate assessment instruments, understanding etiological variables, and examining potential cultural differences in symptom expression of BPD are desirable.[61]

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Conflicts of interest
There are no conflicts of interest.

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Original Article

A Survey among Teachers of Psychiatry to Improve the Quality of Undergraduate Training: Outcomes from Karnataka

M. Kishor, Ashok V. Mysore[1], Mohan K. Isaac[2], H. R. Vinay[3], K. Kiran Kumar[4]

ABSTRACT

Background: In India, there is a large gap between the mental health morbidity in society and the availability of psychiatrists. However, the latest Indian undergraduate medical curriculum does not require any competency in psychiatry to be fulfilled for certification of medical graduates as doctors. Thus, the role of Indian psychiatry teachers is quite challenging. Interestingly, there has been hardly any effort to understand the felt needs of psychiatry teachers that may further improve the quality of undergraduate training. **Methods:** We used a survey questionnaire that was both qualitative and quantitative, with questions on topics such as years of psychiatry training and experience as a psychiatry teacher. Do they feel the need for training in undergraduate psychiatry teaching? Do they require training in teaching psychiatry theory or clinics or both? What are the specific areas where they want training? What more should be planned for psychiatry teachers? Based on an online survey further steps in the direction of psychiatry teachers felt needs were initiated. **Results:** Around 55 responses with a response rate of 37% were received. More than 50% were working in medical colleges for the last 5 years. About 80% felt the need for further training to teach medical students while 97% felt that additional training is required for handling theory as well as bedside clinic. More than 60% were keen to attend a 1-day workshop to upgrade their teaching skills. A majority wanted to have a forum to share their experiences and to learn from others. Based on the felt needs of psychiatry teachers from the survey, a 1-day workshop was carried out and a forum for psychiatry teachers was inaugurated. **Conclusion:** Training of psychiatry teachers is an important felt need for the challenges that are unique to Indian medical education. The outcome from the Karnataka survey is a progressive step in addressing this challenge.

Key words: *Indian teachers of psychiatry, teaching skills, undergraduate medical education*

Key message: *Training in teaching undergraduate theory and clinics is a felt need of teachers of psychiatry and a forum of teachers to foster more interactions is thereby needed to empower them to handle challenges that are unique to Indian medical education.*

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The World Health Organization estimates that in India, the economic loss, due to mental health conditions, in the year 2012–2030, would be 1.03 Trillion US Dollars.[1] With a 1.35 billion population, the burden of mental health problems is of the tune of 2,443 DALYs per 100,000 populations, and the age-adjusted suicide rate per 100,000 populations is 21. However, the number of psychiatrists per 100,000 populations is 0.3.[1] Paradoxically, even with such a large gap between the mental health morbidity in the society and the availability of psychiatrists, the latest Indian undergraduate medical curriculum mentions that nothing in psychiatry is required for certification of medical graduates as doctors.[2] This is a matter of concern as it impairs upcoming medical doctors in India to manage common mental health conditions. Efforts to incorporate psychiatry as a mandatory part of the evaluation in medical education have failed despite the repeated efforts of the Indian Psychiatric Society over the last several years.[3]

India has 528 medical colleges, one of the largest in the world with more than 70,878 admissions annually.[4] With a minimum of three psychiatry faculty per medical college, if the annual intake is 100 MBBS students and higher the number of faculty if the intake is higher, particularly so in 200 plus medical institutions which offer additional psychiatry postgraduate residency, it is estimated that there are 2500–3000 psychiatry teachers in Indian medical colleges. The challenges of Indian psychiatry teachers are many.[5] The need to train psychiatry teachers were highlighted 30 years ago.[6] However, there has been hardly any effort in India to understand the felt needs of psychiatry teachers concerning their skills in teaching theory and clinics that enhances their ability to engage medical students. Hence, an online survey for psychiatry teachers was planned. Based on an online survey, further steps in the direction of psychiatry teachers felt needs about training were considered.

METHODS

After obtaining the institutional ethical committee approval, wherever it is applicable a survey was carried out in the state of Karnataka in 2016. The questionnaire had both qualitative and quantitative information. The questions were as follows: how many years of psychiatry training (DPM, MD, DNB, or a combination)? How many years of experience as a psychiatry teacher? How many hours do they engage in undergraduate teaching? Do they feel the need for training in undergraduate psychiatry teaching? Do they require training in teaching psychiatry theory or clinics or both? Are they interested in a workshop for the same? Are they willing to pay for the training? What are the specific areas in which they want training? What more should be planned for psychiatry teachers? The questionnaire was posted on many electronic platforms such as e-IPS groups (which are an online group of Indian Psychiatric Society), personal emails, and other means for communication to medical college psychiatry teachers in Karnataka and hard copies dispatched to, whoever preferred so. Those who consented to participate in the study were included. Confidentiality of personal and institute affiliation details was assured.

RESULTS

Around 55 responses were received. Considering that in 2016 there were 52 medical colleges in Karnataka and the minimum number of psychiatry faculty who were engaged in teaching is two or three per institution (approximately 104–156 faculty in total), the response rate was 37%. More than 50% of responders had done MD in psychiatry and have been working in medical colleges for less than 5 years [Figures 1 and 2]. More than 80% (n = 47) felt the need for further training to teach medical students [Figures 3 and 4]. Nearly all felt that additional training is required for handling theory as well as bedside clinic. More than 60% (n = 35) were keen to attend a 1-day workshop to upgrade their teaching skills [Figure 5]. Nearly 70% (n = 38) were willing to pay a fee of 500–1000 INR for a 1-day workshop. The majority wanted to have a forum to share their experience and learn from others. On the qualitative data concerning areas, the psychiatry teachers felt the need for discussion in the proposed workshop; the following are reproduced as it is: "Need to know what should be psychiatry syllabus for MBBS students," "Psychiatry teaching that is appropriate for different phases of MBBS," "Different models of teaching psychiatry," "What should be teaching-learning engagement in Internship?" "What are innovative methods in teaching theory and clinics?" "How can we make psychiatry teaching more interesting?" "How can we incorporate the interest of students such as preparation of entrance examination/quiz preparation or research interest?" and "How to assess undergraduate learning?". Based on the felt needs of psychiatry teachers

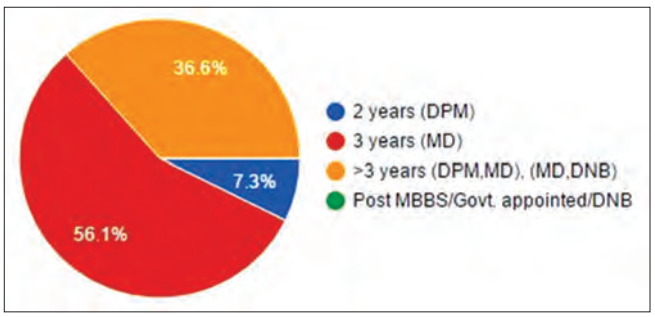

Figure 1: Psychiatry teacher's years of psychiatry training

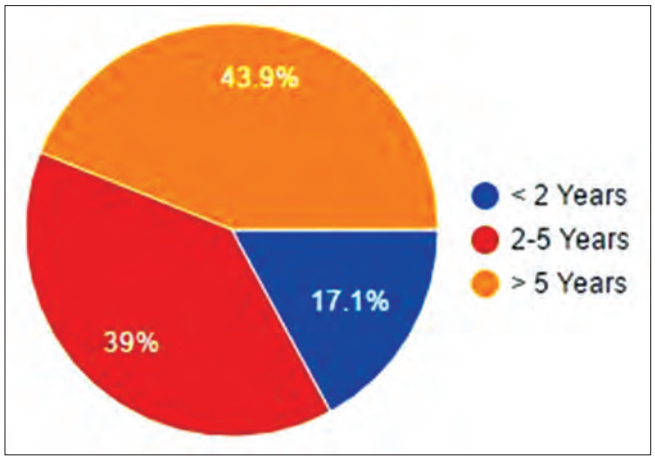

Figure 2: Psychiatry teacher's years of experience as a faculty

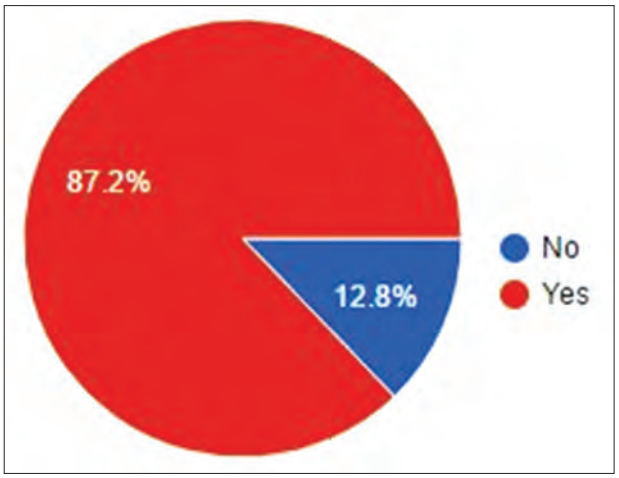

Figure 3: Felt need of psychiatry teachers for training in undergraduate teaching

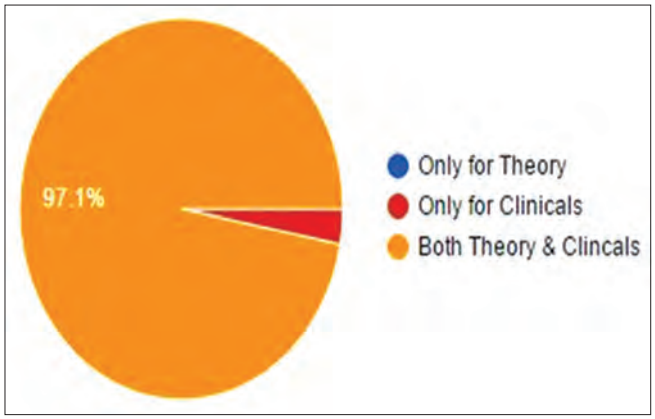

Figure 4: Felt need of psychiatry teachers for training in undergraduate theory and clinics

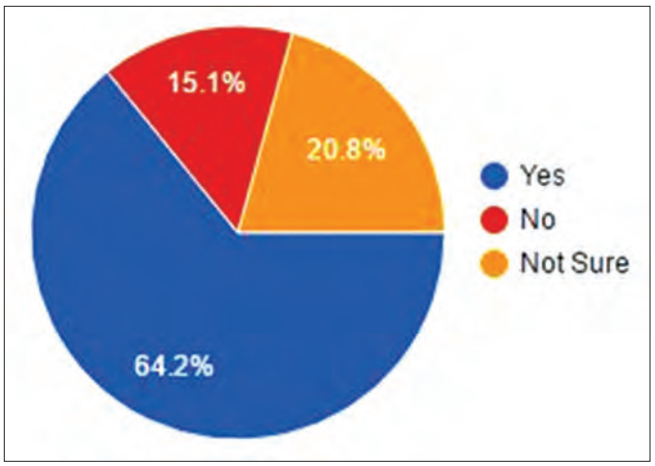

Figure 5: Psychiatry teacher's interest in attending a 1-day workshop for teaching skills

from the survey, a 1-day workshop was carried out and a forum for psychiatry teachers was inaugurated.

DISCUSSION

More than one-third of psychiatry teachers from Karnataka participated in the survey. It is difficult to precisely estimate the number of faculty in each medical college since the Medical Council of India specifies a different requirement for undergraduate institutions which varies with the number of intake of MBBS students. Moreover, those departments with postgraduate teaching faculty vary depending upon the annual postgraduate intake approved for that institution. Institutions may or may not have more faculty than required. With these limitations, considering that in 2016 there were 52 medical colleges in Karnataka and the minimum number of psychiatry faculty who were engaged in teaching is two or three per institution, the response rate was encouraging. Karnataka has a distinction of the maximum number of medical colleges in India and experience from this state may be useful to replicate in the other states.

Those teachers who did not participate may have other equally important engagements such as patient care services in the teaching hospitals where they work or in research activities or other academic activities (e.g., NAAC-National Assessment and Accreditation Council) expected. Our findings reiterate the fact that unlike nonteaching psychiatrists, those affiliated to medical colleges have multiple roles to carry out which may be affecting their role in teaching undergraduates.[5] The majority of the responders had 3 years of training in psychiatry with less than 10% with 2 years of diploma. As the Medical Council of India is planning to phase out a postgraduate diploma, only the MD/DNB (Diploma in National Board) residency may remain. These 3 years of training can be utilized for incorporating teaching skills at the earliest especially in DNB, training awarded from nonteaching hospitals. Most of the faculties were young teachers; 56% with a teaching experience of fewer than 5 years. This is in line with the findings of the 2013 Indian Psychiatric

society task force on postgraduate education under Prof Mohan Isaac who noted that most faculties engaging in teaching were young. It can also be that senior faculty may have many responsibilities such as administrative works of department or less active online to respond to the survey.

Around 12% of the faculty did not feel the need for training in teaching psychiatry to MBBS students. As the survey did not collect the reasons for the same, it is presumed that these faculty may have received some training such as the Medical Council of India mandatory basic course in medical education technology that is carried out for 3 days in all medical colleges for teachers on a rotation basis.[7] Although there is no data on how many psychiatry faculty in Karnataka have completed this training, our study did not collect data on this aspect.

The majority of responders, (87%, $n = 48$) felt the need for training to teach psychiatry for MBBS students. Probable reasons could be, in India until the last few years most of the psychiatry residency was offered in psychiatry institutes such as the National Institute of Mental Health and Neurosciences (NIMHANS) or Central Institute of Psychiatry (CIP) which are not affiliated to medical colleges. It is important to note here, apart from NIMHANS which is situated in Karnataka, until the year 2006, only four medical colleges in the state offered a postgraduate residency in psychiatry. Hence, the exposure of psychiatry faculty to undergraduate training was absent or limited to a large extent. Even today a good number of psychiatry faculties from these centers may feel the need for training. The other reasons could also be the absence of any focused training in undergraduate psychiatry or constraints associated with limited period available and lack of enthusiasm among students as psychiatry is not among the mandatory subjects for examination. Interestingly, almost all psychiatry teachers felt that they needed training both to handle theory and bedside clinics. This is understandable as the skills and methods for theory and clinics are different, especially so in psychiatry. The allotted 20 h, in theory, is too little for teachers to incorporate many important topics in psychiatry. Even the clinical exposure is short and limited to one continuous posting of 20 days in the entire MBBS training period. Such constraints may be the reasons for the majority responder's need for training in both patterns. This emphasizes the need for psychiatry teachers to do their best to start from the basics of history taking to imparting limited skills in the mental status examination within the limited exposure the students get in psychiatry. However, the new competency-based curriculum has greatly enhanced the duration of exposure to psychiatry. The curriculum is divided into 19 topics and 117 outcomes.[2] Hence, it may be even more important to address the felt needs of psychiatry faculty to upgrade their skills.

As expected, 64% of the faculties were keen to attend a 1-day workshop to upgrade their psychiatry teaching skills. Around 20% were not sure of whether they should be attending the workshop. This may be because psychiatry faculties are less in number in each institution and they have to manage outpatient and inpatient services as well. Among those who wished to attend a 1-day workshop, 70% were willing to pay 500–1000 INR. Nearly 20% felt that no fee should be charged. Probably, psychiatry faculties felt that the institution or professional organizations should take responsibility. However, this study has not collected more information on financial resources.

Interestingly, the varied needs of psychiatry teachers for a workshop such as "Different models of teaching psychiatry," "What should be the teaching-learning method," "What innovative methods are in teaching theory and clinics?" and "How can we make psychiatry teaching more interesting?" This greatly enhances our understanding of a focused approach towards each need that is sometimes unique to India.[8] It is for the first time we can consider and understand psychiatry training from the teachers' perspective. Moreover, solutions to the needs of psychiatry teachers can come from the teachers themselves if there is a platform for teachers in India to share their experiences; unfortunately, there are no such focused forums.[9] The majority from the survey, on the question of what more should be done for psychiatry teachers, expressed the need for continued efforts to make psychiatry mandatory; they felt the formation of the forum for teachers to discuss the issues that are unique to psychiatry teachers, to have periodic workshops and seminars, etc.

Based on the survey, a 1-day workshop for undergraduate teachers of psychiatry was conducted on 27th November 2016 at Department of Psychiatry, St. John's Medical College, Bengaluru, Karnataka under the collaboration of Indian psychiatric society-Karnataka chapter; Medical Education Department, St John's Medical College (Medical Council of India Regional center for medical education); Rajiv Gandhi University of Health Sciences, Government of Karnataka. The program was also attended by the Director as well as Head of Psychiatry, National Institute of Mental Health and Neurosciences, Bengaluru. It is interesting to note the presence of all stakeholders involved in Indian psychiatry training that acknowledges the felt need of psychiatry faculty and encourages efforts to train them. More than 50 teachers of psychiatry participated in the workshop. About 22 female and 34 male psychiatry

faculties were present in the workshop. Among them 10 heads of department were present. Besides, four professors, six associate professors, 23 assistant professors, and 13 senior residents were present. In total, the participants represented 20 medical colleges and five universities of the state. A forum of Indian Teachers of Psychiatry was inaugurated.[10] In the workshop on teaching theory and clinics, articles on innovative teaching methods and e-resources were also provided.[11,12] Based on the skill enhancement workshop participants interest an online group was formed to share the experiences of interested psychiatry teachers.[13] The psychiatry teachers' training experience from Karnataka was shared at the state psychiatry conference and in the national psychiatry conference, a joint symposium representing various southern states for similar initiatives that involved each state to gather the felt need of psychiatry teachers training through a survey was discussed.[14,15]

Teaching the teachers in psychiatry is much emphasized in the west; in India, efforts such as this study are less.[16] The result from the survey reiterates the much- needed training in teaching skills as felt by the psychiatry teachers in India.

To conclude, the teachers of psychiatry felt the need for training in teaching skills and they participated in a workshop when an opportunity was provided, despite the challenges that are unique to psychiatry in Indian medical education. Although the survey is restricted to the state of Karnataka and only 37% faculty responded which is a major limitation, larger systematic studies across India are needed. It is encouraging to note the felt needs of psychiatry teachers to upgrade their skills. The limited progress made from the Karnataka survey findings, subsequent workshop, and the formation of a forum of Indian teachers of psychiatry to improve the quality of mental health training is an important step in the Indian scenario.

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Conflicts of interest
There are no conflicts of interest.

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Viewpoint

Juvenile Justice System, Juvenile Mental Health, and the Role of MHPs: Challenges and Opportunities

Gupta Snehil, Rajesh Sagar[1]

ABSTRACT

Juvenile justice system (JJS) and the mental health of the juveniles involved in it are intricately related. Children in conflict with the law (CICL) and children in need of care and protection (CINCP) have a higher prevalence of mental health-and substance use related—problems, similarly, juveniles with mental health problems have a higher chance of coming in contact with JJS. Juvenile Justice Act, 2000 (JJ Act), with its latest amendment (2015), emphasizes the developmental well-being, including the psychological well-being of juveniles coming in contact with JJS and their social reintegration and rehabilitation. Mental health professionals (MHPs) can play a significant role in realizing this goal by contributing at all the levels: mental health promotion, preventing juveniles from coming in contact with JJS, treating juveniles in contact with JJS, and subsequent rehabilitation. Being well-versed in this area would also give a clinical and legal edge to the MHPs. Although JJ Act is a child-friendly law, its implementation in the real-world is faced with many practical challenges, which in turn limit or undermine the full legal, social, educational, and health benefits to the juveniles. The current viewpoint is aimed to highlight the important mental health aspects of juveniles involved with JJS with reference to the JJ Act (care and protection of children act, 2015) and the potential role that MHPs can play and discusses important challenges and road ahead.

Key words: *Child mental health, JJ Act (Care and Protection of Children, 2015), juvenile delinquencies, juvenile justice system, mental health professionals*

Being the future of any society and a vulnerable section, children deserve laws that could ensure their developmental well-being. Many children-centric laws do exist in India, such as Child Labour Act (1993),[1] Juvenile Justice Act (JJ Act, 2000), Prohibition of Child Marriage Act (2006),[2] Right of Children to Free and Compulsory Education Act (2009),[3] and Protection of Children From Sexual Offences Act (POCSO, 2012).[4] Among these, JJ Act deals with 'children in need of care and protection (CINCP)' and 'children in conflict with the law (CICL),' i.e., juveniles involved with Juvenile

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Justice System (JJS). Literature suggests that at some juvenile justice contact points, as high as 70% of the youth have a diagnosable mental health problem. The commoner ones include externalizing disorders such as to conduct disorders (40.9–64.7%), attention deficit hyperkinetic disorder (ADHD, 4.1–19.2%) or substance use disorders (40.2–50.4%); and internalizing disorders such as anxiety disorders (30–38%) and mood disorders (7.3–13.9%). Externalizing disorders increase the likelihood of juvenile delinquency, violence, and recidivism.[5-9] In contrast, early identification and intervention are associated with a decreased rate of recidivism and better social integration.[6,10]

Individuals involved in providing care to such juveniles in the observation homes or child care institutions (CCIs) are often untrained and unskilled and lack on-job support from the mental health professionals (MHPs) to recognize and address the psychological needs of such juveniles.[11] This, to a certain extent, also holds true for the members of the justice system board (JJB) and officers of the child police protection unit (CPPU) of the district. This comes as a great challenge on the path of providing holistic and comprehensive care to the juveniles coming in contact with JJS. Therefore, the proactive role of MHPs becomes far more important in training, skill development, and capacity building. Moreover, it is also not uncommon for MHPs to come across such juveniles during their clinical practice or when called as an expert in the court of law.

Despite the existence of the JJ Act in India for more than two decades, the latest amendment for the last four years, and its clinical and legal implications for the MHPs, the literature is scarce from Indian psychiatry. The literature is mostly from social science or legal schools.[11-13] Furthermore, the literature available from the mental health field is skewed towards the mental health of the CICL,[9,14] while the mental health aspects of the CINCP (orphans or adoptees) remain untouched.

This review attempts to highlight the relevant sections of JJ Act (care and protection of children act, 2015), emphasizes mental health aspects of the juveniles involved with JJS and the potential role that MHPs can play, discusses the contentious issues, and also provides some way forward.

METHODOLOGY

Literature was searched with the help of academic search engines such as PubMed and Google Scholar' using search terms such as"Juvenile delinquency OR juvenile justice system" AND "Mental health OR Mental health professionals." A total of 93 results were obtained; however, only seven articles were

available from India, including one full-text article obtained by contacting the author,[14] one book,[15] and one document.[16] Gray literature was searched by visiting government departments (Ministry of Women and Child Development, National Commission on Protection of Rights of the Children [NCPCR], and Integrated Child Protection Scheme [ICPS]) and legal agencies' websites. The review narratively highlights and discusses the evolution of the JJ Act of India, the JJS from the mental health perspective of juveniles, challenges in bridging the gap between the mental health need of the juvenile involved with JJS, and the opportunities and road ahead.

RESULTS

Juvenile Justice System and evolution of the Juvenile Justice Act of India

India enacted the JJ Act for the first time in 1986. It prohibited the sentencing to prison of any CICL under any circumstances.[16] India, being a signatory of the United Nations Convention (1992) for the rights of the child,[17] ratified the treaty by passing the JJ Act (Care and Protection of Children) in 2000, incorporating the international standards to deal with CICL and CINCP.[18] The Act ensures proper care, protection, and treatment to the children by catering to their development needs and by adopting a child-friendly approach in the adjudication and disposition of matters in the best interest of children. Further, it mandated the ultimate rehabilitation of such children through various institutions established under this enactment.

The Act underwent amendments in 2006, 2010, and 2015. The major changes have been described below:

Highlights of the amendments of JJ Act (2006)

This amendment makes a provision that "if a child who commits an offense while being juvenile and

apprehended after the cessation of juvenility, the child should be treated as a juvenile" (considering their physical and mental immaturity at the time of committing an offence). It entrusts the state governments to review (on a six-monthly basis) the number of the pending cases under JJ Act, expedite the process of trials, constitute an adoption center in each district, and establish child protection unit in each district and hold the unit accountable for the implementation of the Act in each district and also encourages the adoption of CINCP and promotes it as a rehabilitative measure.[19]

Highlights of the amendments of JJ Act (2010)

This amendment omits the provision from the Act that ruled for the "separate treatment of juveniles or children suffering from leprosy, sexually transmitted disease, hepatitis B, tuberculosis, or children with unsound minds." It regulates the power of the competent authority of the special homes to move a child from special homes to a special facility like a mental health institution.[20]

Highlights of the amendments of JJ Act (2015)

Some of the major amendments and relevant aspect of of the Act are as follows:[21]

The Act defines the CINCP as one "who is mentally ill or mentally or physically challenged or suffering from a terminal disease and having no support system (parents or guardians) if found so by the Juvenile Justice Board (Board) or the Child Welfare Committee (CWC)."

Furthermore, the Act describes the principles to be followed while dealing with juveniles involved with JJS. It includes treating children with dignity and rights, maintaining their privacy and confidentiality during the various processes of juvenile justice, ensuring their safety, considering institutionalization as the last resort only, focussing on restoration, and keeping a non-stigmatizing attitude towards them.

The Act also describes the structure and qualifications for the members of the Juvenile Justice Board (JJB). The Act mandates that the non-magistrate board members (two in number) should have experience (of at least seven years) in the field of health, education, or welfare activities pertaining to children or be a practicing professional with a degree in child psychology, psychiatry, sociology, or law.

One of the important amendments in the Act is with regard to the procedure to be followed in case a heinous offense is alleged to have been committed by a child of age <16 years. As per the amendment, a preliminary assessment with regard to the mental and physical capacity of the juvenile should be conducted to determine the juvenile's ability to understand the consequences of the offense and the circumstances in which he/she allegedly committed the offense. If the board finds (the board may take the assistance of mental health or other experts) that the child had the capacity to commit a heinous offense, it may order to conduct a trial on the child as an adult.

The Act also mandates that no person shall be appointed as a member of the Child Welfare Committee (CWC) unless such person has been actively involved in health, education, or welfare activities pertaining to children for at least seven years or is a practicing professional with a degree in child psychology or psychiatry, law, social work, sociology, or human development.

It also framed law with regard to the procedure to be followed in relation to CINCP. The Act mandates that any individual (including doctor) or organization (including nursing homes or hospital) who/that finds a CINCP shall, within 24 hours (excluding the time necessary for the journey), give the information to the child-line services, the nearest police station, a CWC, or the CPPU, or hand over the child to a CCI registered under this Act. Non-compliance with the rule is liable for punishment (with imprisonment up to six months, fine of ten thousand rupees, or both).

Moreover, the Act states that the juveniles should be provided rehabilitation and reintegration services by institutions registered under this Act. It also mandates that the institutions should provide mental health interventions, including counseling specific to the needs of the child.

One of the important parts of the Act is the one which talks in detail about adoption and the procedure to be followed. It rules that adoption shall be resorted to for ensuring the right to family for the orphan, abandoned, or surrendered children.

One of the relevant aspects from the health providers' perspective is the prohibition of disclosure of the identity of the children registered under juvenile justice law. Any person found to be in contravention of this is liable for punishment (with imprisonment for a term that may extend to six months, a fine that may extend to two lakh rupees, or both).

Lastly, it describes the provisions for moving a child from special homes to treatment centers for mental illness or substances use related problematic behaviors.

Important mental health aspects of the juveniles involved with JJS and the potential role of MHPs

The mental health of the CICL and their delinquent behaviors are interrelated. This could be attributed to their shared biopsychosocial vulnerabilities or one condition exacerbating the other.[22,23] Non-addressal of these interrelated factors leads to subsequent recidivism and poor functional outcomes.[24] Hence, addressing the mental health needs of such juveniles is of utmost importance. It cannot be overemphasized that MHPs can contribute significantly in preventive, therapeutic, and rehabilitative fronts apart from their advisory role in JJS. Fortunately, JJ Act (2015 amendment) has given due weightage to this aspect and mandated no social worker to be appointed in the JJ Board or the CWC until one has experience in education or is a practicing professional with a degree in child psychology, psychiatry, sociology, or law.

The JJ Act (2015 amendment) rules that a preliminary assessment should be ordered for the mental and physical capacity of the juvenile aged 16-18 years alleged to have committed a heinous crime. The Board may take the assistance of experienced psychologists or psychosocial workers or other experts. Literature suggests that adolescents aged >14 years (Vs. <14 years) coming in contact with the law have more mental health issues.[25] Because MHPs are frequently called as an expert in such cases, their role becomes crucial, especially when such incidents get highlighted in the media and the legal procedure is likely to get influenced by various agencies (e.g., Nirbhaya's case, 2012).

The Act mandates that confidentiality should be maintained while dealing with juveniles in contact or likely to come in contact with JJS, to avoid litigation. This is in sync with the latest Mental Healthcare Act (MHCA, 2017), which also emphasizes maintaining the confidentiality and autonomy of a person with mental illness.[26] Since MHPs are frequently involved in assessing mental health and providing care to juveniles involved with JJS, exercising confidentiality is of paramount importance to avoid untoward legal complications.

Rehabilitative and re-integrative services form the core of the JJ Act. It mandates the registered childcare institutions to have mental health care facilities and referral facilities to mental health and de-addiction centers. The MHPs providing care to such juveniles are expected to prepare a comprehensive plan for ensuring quality and continuity of care.

The adoption rule of the JJ Act (amendment, 2015) gives weightage to the emotional needs and wishes of the child deemed fit for adoption. Adopted children are at a heightened risk for problematic externalizing behavior, neuroses, social incompetence, and poor educational performance (vs. non-adopted counterparts).[27-30] Some of these problems are related to early childhood and pre-adoption institutionalization-related stressors.[30] Hence, addressing mental health issues at both the pre- and post-adoption stages are important, and the role of MHPs in this context cannot be overemphasized.

The Act also rules that as and when required, a juvenile can be moved to a mental health facility (including de-addiction centers) for the necessary treatment. However, the MHCA 2017 rules that any person with age <18 years should be treated as minor and be admitted with a nominated representative, forming the advance directives for the child.[31] With two parallel acts in force, the MHPs should remain updated about the laws because they have clinical and legal implications. Formulating a comprehensive post-discharge plan is important to ensure continuity of care at the CCI or at the community, to minimize the worsening of psychological/behavioral problems and re-institutionalization.

Challenges in bridging the mental health needs a gap of the juvenile involved with JJS

JJ Act has an inherent flaw as it attempts to address the rights of CICL and CINCP within the same system.[11] This brings about an ambiguity among the personnel involved with JJS (including CPPU) in the absence of a clear distinction between the two similar populations with different needs. It is not uncommon for juveniles with intellectual disabilities or mental illnesses to get detained and placed in observation homes. It only adds to the suffering of the CINCP. Hence, a better understanding and a different approach for CINCP should prevail.

Although the Act rules that the basic needs of the children involved with JJS (including their mental health needs) should be ensured, it seems far from achieving in the real world. Lack of understanding about child psychology (normal childhood or deviant behavior) and skills among the CPPU, social workers, and staff of the CCIs are important limiting factors.[11,14] In the absence of access to training or required skills, staffs of CCIs tend to resort to harsh behavior and punitive actions as a form of corrective measures.[11,14] Hence, orientation and on-job training to the staff of the CCIs are important.

Poor budget allocation to the institutes/non-government organizations (NGOs) running CCIs is another important limiting factor as they receive a meager grant.[11] However, in its revised scheme, integrated child protection scheme (ICPS) has increased the budget to

Rs 2,000 per child per month, but its implementation and impact in the real world are yet to be seen.[32]

Though JJ Act rules that registered CCIs should have basic mental health facilities, including specific need-based counseling, many institutions run without regular qualified MHPs, and the available MHPs are either volunteers or associated with the NGOs providing supplementary services like health, recreation, etc.[11,14,16] More so, the practice of continuity of care post-discharge hardly exists. A research conducted by the National Commission for Protection of Child Rights (NCPCR) (2018) in the national capital region (NCR) highlighted that children in child-care homes face many mental traumas in the form of bullying by the seniors, sexual abuse, overcrowding; their foods have unspecified nutritive value, they lack tutors for education and dedicated MHPs to assess their mental health needs.[16] This mandates periodic monitoring of the child-care homes registered or unregistered under the JJS. Though ICPS has taken steps in this line, its outcomes are yet to be seen.

There is a growing incidence of juveniles from Lesbian, Gay, Bisexual, and Transgender (LGBT) communities or with gender identity issues coming in contact with JJS in India.[11] Western literature suggests that the mental health needs of such juveniles are often overlooked, despite them suffering the bullying of the senior inmates and humiliations by the staffs of the institution and being at heightened risk of mental health problems.[33] Data are scarce from India in this regard, but this should not preclude us from exploring and addressing these aspects. MHPs can definitely play a major role in this regard in terms of training, clinical care, and research.

Realization of the holistic care and rehabilitation of the juveniles involved with JJS becomes challenging, as it requires coordination among different agencies such as legal, health, social justice, and educational systems, which at times may have varying and competing goals. Hence, establishing coordination and sensitizing them about the biopsychosocial aspects of juvenile delinquent behaviors could, to a certain extent, bridge this gap[7,11,13] and help in leveraging the available resources. The role of MHPs in this regard cannot be overemphasized.

Stigma is another major hurdle, as the community often considers such juveniles as 'wicked,' 'threatening,' or of 'bad character'[34] and prejudice d them based on their socio-economic status and ethnicity.[11] This leads to marginalization and they getting deprived of the much needed social support and re-integration.[35] Moreover, exaggerated negative portrayal of such juveniles in public media further adds to their stress and worsens their psychological and behavioral problems.[36]

Although JJ Act mandates the maintenance of confidentiality, its violation is not uncommon in our country. MHPs can play a vital role in spreading awareness in the community and advocate for responsible reporting by media; this would help in reducing stigma, thereby preventing psychological and behavioral problems among juveniles and facilitating their rehabilitation.

Lack of awareness about the mental health issues and treatment options also deprive juveniles of early intervention. Western literature suggests that juveniles involved in delinquent behavior or with mental health issues (and their family members) often think that the problems would self-resolve or remain unsure about the treatment.[37] This results in a delay in seeking help till the time such juveniles come in contact with the JJS. Hence, mental health promotion (primary prevention), early identification, and intervention (secondary prevention) become imperative.

Continuity of mental health care and rehabilitation in the community is a crucial aspect for the juveniles involved with the JJS. The socio-cultural milieu of the CICL reinforces their delinquent behavior and exacerbates their mental health problems. Lack of community participation hampers their social reintegration and rehabilitation and increases the frequency of institutionalization and recidivism.[12] Literature suggests that community-based and family-focused interventions (e.g. multisystemic therapy) have favorable mental health outcomes and significantly reduce the rate of juvenile delinquencies.[38] The NCPCR, through ICPS, has taken certain steps such as the provision of open shelter homes and family counseling, but its field level implementation and outcome need to be ascertained.[32]

Opportunities and the road ahead

A standardized curriculum should be developed for the personnel working with a juvenile in contact with JJS in the child care homes (or at the CPPU) and that should include: orientation about child psychology and the different psychological needs of the CICL and CINCP, skill development in identifying and addressing psychological issues of the juveniles, and on-job-training by the MHPs.

A simple, comprehensive screening tool should be developed to screen for mental health disorders (including substance use problems) among all the juveniles at their entry point and which can be applied by even non-MHPs with minimal training.

Capacity building of the CCIs should be ensured by appointing MHPs (including child psychologists and social workers) on a regular basis. Further, regular

auditing of the CCIs for the availability of MHPs, quality-checking of the mental health services, and setting accountability for the concerned authority running the institution should be done. This could ensure the availability of the professional workforce. Moreover, increasing fund allocation to the CCIs would be a promising step in this direction.

Entry-level counseling for the juveniles coming in contact with CCIs should be made mandatory. The counseling should include the rationale behind keeping them in the institute, kinds of situations (e.g. possibility of bullying by the senior inmates) they might face during their stay, and who should be the contact person in case of any mental/physical stress.

Training of the juveniles by the peer trainers (ex-residents of the juvenile homes), in line with peer education practiced in substance use treatment programs, could be another novel and viable option. Because the peers often share similar socio-cultural backgrounds, juveniles may be more comfortable interacting with and learning skills from them.

Job- and livelihood-oriented vocational training (vs. outdated vocational trainings) tailored to the interest and skill of the juveniles should be undertaken. Formal bridge courses, digital learning, and technology-driven skill development would be more effective in this context. Sponsored schemes (under Pradhan Mantri Kaushal Vikas Yojana) and involving professional organizations/NGOs could be welcome initiatives.

The preventive strategy should be strengthened for at-risk populations: school dropouts, first-time offenders, and juveniles with externalizing disorders. Community participation and involvement of NGOs in collaboration with MHPs could not be over-emphasized in this regard.

Inter-sectoral coordination among various agencies should be encouraged. Awareness about child psychology and socio-cultural determinants of delinquent behavior and mental health problems can play a pivotal role in changing the attitude of various stakeholders and thereby would facilitate social reintegration and rehabilitation of such juveniles.

More research work from India, including addressing ethical challenges in researching this vulnerable section, is required to identify the magnitude of mental health problems among the juveniles in contact with JJS and to develop potential interventions.

Post-discharge community re-integration can be ensured by community involvement, public–private partnership, and sponsorship schemes; taking various stakeholders (health, education, and law and order) onboard, and by including family members, if available, of such juveniles.

CONCLUSIONS

This work highlights that the JJS and mental health of the juveniles are intricately related. MHPs can play a key role in the promotion of mental health, prevention of mental illness, and thereby, subsequent contact with JJS, therapeutic intervention at the JJS level, and social rehabilitation. Becoming well-versed with the JJ Act (and its amendment) and acting judiciously would give a clinical and legal edge to the MHPs. There are many challenges in ensuring the psychological well-being of the CICL and CINCP. An attitudinal change among the concerned personnel of JJS and their skill-based approach towards juveniles and participation by the community and other stakeholders in liaison with MHPs are the key steps in this direction.

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Conflicts of interest
There are no conflicts of interest.

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Letter to Editor

Development of Restless Leg Syndrome in a Pediatric Patient Treated with Sertraline

Restless leg syndrome (RLS) is characterized by the restlessness of the legs, with an urge to move, which is temporarily relieved by movement and worsened by periods of inactivity and rest. The symptoms are often noticed in the evening and while sleeping at night.[1] Iron deficiency is often associated with RLS,[2] and the treatment consists of replenishment of iron level. There are some data suggesting the role of antidepressants in the development of RLS among adults.[3] However, there is only one report on the development of increased myoclonic leg movement among pediatric patients in the context of treatment with fluoxetine.[4] We present a compelling case of RLS that developed in the context of treatment with sertraline in a child with Crohn's disease. The patient assented to the proposed case report and the mother provided an inform consent.

CASE PRESENTATION

A 9-year-old male with a history of attention deficit hyperactivity disorder (ADHD), generalized anxiety disorder, and Crohn's disease was stable on guanfacine extended-release tablet 2 mg (for ADHD) and sertraline (for anxiety). We had put him on sertraline 6 months ago and had titrated the dose to 37.5 mg about 2.5 months before writing this report. Sertraline helped significantly with the anxiety symptoms but the patient started experiencing uneasiness in his legs within 3 weeks of the increase in its dose. The patient described that his feet "will not stop moving" at night causing initial insomnia. He also described a "crawling," "tingling," and dull aching "pain" all over his legs, especially around feet and ankle, at night. The symptoms disappeared during the day when he is active. He was offered massages, warm compression, and hot bath without much improvement in the symptoms. There were no symptoms of jerky movement of the extremities while sleeping or acute sharp pain in a single group of muscles. The patient did not experience any fever, rash or blood loss and also denied any family history of RLS.

A thorough physical examination conducted by the medical team revealed no abnormalities and there was no swelling, gloves and stock distribution of sensation, or any other local site pathology. Blood work revealed a red blood corpuscle count of 4.62 (range 3.98–5.19 M/mcL), hemoglobin 12.3 (11.2–14.4 g/dL), hematocrit 37.4 (34.0–43.4), mean corpuscular volume 81.0 (range- 78.0–90.0 fL), mean cell hemoglobin 26.6 (25.6–30.2 pg), mean corpuscular hemoglobin concentration 32.9 (31.0–35.0 g/dL), platelets 203 (140–400 K/mcL), mean platelet volume 9.3 (9.0–12.6 fL), C-reactive protein 3.5 (≤1.0 mg/dL), erythrocyte sedimentation rate 24 (0–10 mm/h), ferritin 8 (7.0–140.0 ng/mL), gamma-glutamyl transferase 15 (9–64 IU/L), zinc 67 (48–129 mcg/dL), vitamin D 36 (30–100 ng/mL) vitamin B12 904 (180–914 pg/mL), folate 24.8 (>5.9 ng/mL), iron 44 (62–196 mcg/dL), iron saturation 10 (15–58%), blood urea nitrogen 10 (9–22 mg/dL), and creatinine 0.48 (0.70–1.30 mg/dL).

We applied Naranjo Algorithm- Adverse Drug Reaction (ADR) probability scale, and the score was 8, indicating the likelihood of a probable association[5] of sertraline and the reported symptoms. We diagnosed him with RLS in consultation with his pediatrician. We did not use any rating scales to measure the symptoms. Although RLS is often associated with low iron or ferritin levels, we chose to taper off sertraline because of the temporal relationship between the dose increase of sertraline and the development of the symptoms. The patient started experiencing remission of the symptoms within 2–3 days of lowering the dose of sertraline, and within 7–10 days of discontinuation of sertraline, the symptoms disappeared completely. Although the patient's low serum iron and ferritin levels can be associated with RLS, the symptoms disappeared without any iron supplement, which indicates a possible association of sertraline with the RLS in this case. We wished to further establish the role of sertraline in the development of such symptoms by re-challenging the patient with sertraline but the patient's mother did not provide consent.

DISCUSSION

To our knowledge, this is the first reported case of the development of RLS in a pediatric patient that seems to be associated with treatment with sertraline. Here, RLS developed at a young age, and there was no family history of RLS. The patient had low iron and low normal ferritin levels, which could be related to the development of RLS in this case.

We considered several differential diagnoses. We excluded growing pain because the pain was partially relieved by movement. Venous disorders were not responsible for the presentation because a circadian pattern was present, and there was no venous engorgement or skin alteration at the local site. We excluded akathisia because of the lack of subjective sense of restlessness or inability to sit still and the lack of symptoms during the day. Although we considered polyneuropathy, there was no associated paresthesia or sensitivity to touch, and there was the presence of motor restlessness. The patient did not experience any twitching or jerky movement of the extremities while asleep that is found in periodic limb movement disorder (PLMD). We also considered nocturnal leg cramp but we excluded it because of the bilateral presentation and lack of severe pain and as there was no single group of muscles involved. Crohn's disease can also be associated with RLS but usually, the comorbidity occurs among older patients.[6] In our case, there was no exacerbation of Crohn's disease at the time of appearance of RLS symptoms and neither did the patient require any additional intervention for Crohn's disease symptoms. Although there are some reports of RLS in association with selective serotonin reuptake inhibitor (SSRI) medications, it is unclear whether all antidepressants carry the same risk of RLS.[3] In a qualitative review of medication-induced RLS, escitalopram and fluoxetine were found to have the most substantial evidence for SSRI-induced RLS.[7] There is one study among adult patients,[8] where the incidence of RLS among sertraline treated patients was documented as only 0.9%. However, there was no reported data on pediatric patients.

Although this case report lacks the strength of a definitive causal association of sertraline with RLS, it aims at raising awareness among clinicians about the possible influence of sertraline in the development of such symptoms in pediatric patients.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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Comments on "Pattern and Correlates of Depression among Medical Students: An 18-Month Follow-up Study"

Dear Sir,
As medical teachers and mental health professionals, we read this study with great interest. Although many previous studies have already reported a high level of stress and psychological morbidities in medical students, to our knowledge, this is the first study to longitudinally explore the above issue to assess the effect of the time spent in the medical course on the mental health status of medical students.[1] However, we opine that the following points should be considered while interpreting the results of this study.

The tool used in this study to detect depression, i.e., Patient Health Questionnaire (PHQ)-9 has 88% sensitivity and 88% specificity in cross-sectional designs, but its validity in longitudinal studies is yet to be established.[2] Among 348 medical students eligible for participation for this study, the assessment for depression could be completed in 325 (at 2 months), 279 (at 8 months), and 320 (at 18 months). It is important to know whether the characteristics of the students who dropped out at the second follow-up (8 months) and were available again at the last assessment (18 months) did differ significantly from those continued with the study at all the points of assessment.

While the use of substances other than alcohol, particularly cannabis, is common among professional course students, alcohol was the only substance investigated in this study. A recent survey conducted anonymously among students of a medical school in Kerala had found an increased use of cannabis among those diagnosed with mental health conditions.[3] Because the pattern of "use" of alcohol is not mentioned in the study, it is not possible to know whether it was more problematic (at abuse or dependence level) in those who had depression than those who did not have it.

This study assessed many socio-demographic and family-related variables, but not the family history of psychiatric illness, especially mood disorder. This information is more desirable, given the high prevalence of depression it found.

The authors have mentioned in the discussion part that the association of "unemployed mother" with the increased prevalence of depression in the students was due to financial difficulties of the family. We don't agree with the above explanation as the study has not found any significant association of "student loan" with depression. Therefore, we propose an alternative explanation that it is a type 1 error because of the many variables included and the absence of statistical correction.

To conclude, we appreciate the efforts of the investigators. However, certain issues, as mentioned above, need to be considered while planning similar studies in the future.

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Nil.

Conflicts of interest
There are no conflicts of interest.

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Authors' Responses to the Comments on "Pattern and Correlates of Depression among Medical Students: An 18-Month Follow-Up Study"

Dear Sir,

We would like to thank the authors of the letter for the interest shown in our study and the comments. This was a study with three assessments for mental health measures overtime on medical students. The Patient Health Questionnaire (PHQ)-9 was employed as a cross-sectional measure of depression at each of the three assessments. Recently, investigators have employed the PHQ in a similar manner in medical students,[1,2] though there has been no effort to validate its repeated use.

The limitations due to attrition or non- response to specific scales at the follow-up assessments are already mentioned in the study.[3] Following your comments, we re-examined the data. On multivariate analysis, students lost to follow-up or who did not complete the PHQ were more likely to be from the government college ($P < 0.001$, OR = 7.14[2.86–20]) and of the male gender ($P = 0.006$, OR = 2.01[1.22–3.22]) at the second (8 months) and third (18 months) follow-ups, respectively. Otherwise, the two groups were comparable across baseline variables such as religion, personal choice of course, initial depression status, level of perceived support, and presence of alcohol intake. The variation in the number followed up between the colleges (government vs. private) may be explained by the gaps in the data collection. The implication of data from males being more likely to be missing in the third assessment may be viewed as possibly significant, though the nature of this significance is open to conjecture.

We agree that cannabis use has risen significantly in the state and may have mental health implications, as mentioned in the letter. However, the focus of the study was mental health measures (depression, burnout, and empathy [unpublished]) and the study was envisaged in 2012. At the time, there was no clear evidence of significant cannabis use among young medical students in Kerala, with studies having been published mainly from northern states in India.[4,5]

It would have been interesting to enquire about a family history of mental health issues, particularly depression, in view of the focus of this publication.

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Conflicts of interest

There are no conflicts of interest.

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Nonfasting Lipid Profile May Suffice to Manage Dyslipidemia

Chittaranjan Andrade

ABSTRACT

Patients with major mental illness and especially those who receive antipsychotic drugs are at increased risk of metabolic syndrome. Dyslipidemia is part of the metabolic syndrome. Dyslipidemia is associated with an increased risk of cardiovascular, cerebrovascular, and other diseases. A fasting lipid profile is traditionally ordered to determine the need for and to monitor lipid-lowering treatment. However, a recent study showed that fasting and nonfasting lipid levels, obtained from the same patients, almost identically predicted hard 3-year cardiovascular event risks; the risks with fasting and nonfasting levels were closely similar in various secondary analyses, as well. This supports the stance of major medical associations in the field to accept nonfasting lipid levels to guide the treatment of dyslipidemia in the primary and secondary prevention of cardiovascular and cerebrovascular disease events.

Key words: *Cardiovascular disease, cerebrovascular disease, dyslipidemia, fasting lipids, metabolic syndrome, nonfasting lipids, primary prevention, secondary prevention*

Patients with major mental illness, especially schizophrenia, have risk factors for the metabolic syndrome. Many psychotropic drugs, especially antipsychotics, increase weight and predispose to metabolic syndrome. Dyslipidemia is part of the metabolic syndrome and predisposes to hypertension, ischemic heart disease, stroke, Alzheimer's disease, and other conditions. Lipid levels therefore need to be assessed regularly in patients at risk and primary prevention treatment instituted, where indicated.[1]

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Patients seldom visit psychiatrists in a fasting state; so, if a fasting lipid level is ordered, patients will need to make a second visit. Diabetic patients risk hypoglycemia if they fast unnecessarily. Given that most people are not in a fasting state across the course of the day, might it make more sense to obtain nonfasting lipid levels than fasting lipid levels? This could provide a more meaningful estimate of average triglyceride levels without much biasing the estimation of low-density lipoprotein cholesterol (LDL-C).

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In this context, the use of fasting vs nonfasting lipid levels to predict hard cardiovascular (CVS) outcomes in the same patients was for the first time investigated by Mora *et al*.[2] The sample was a *post hoc* prospective follow-up of a randomized control trial that included 8,270 of 10,305 patients in the Anglo-Scandinavian Cardiac Outcomes Trial-Lipid Lowering Arm (ASCOT-LLA). Of these, 6,855 patients had no prior history of CVS disease. The mean age of the sample was 63 years. The sample was 82% male. The mean body mass index was nearly 29. Smokers comprised a third of the sample. Fasting and nonfasting lipid levels were assessed four weeks apart.

The patients were followed for a median duration of 3.3 years, during which period 351 CVS events were recorded, including 212 major CVS events. Statistical analyses were adjusted for CVS risk factors. The authors obtained several important findings:

1. The mean LDL- C level was only 3–7 mg/dL lower in fasting relative to nonfasting patients, depending on whether it was estimated by the Friedewald or the Martin-Hopkins equation. The mean triglyceride level (124 vs 159 mg/dL), expectedly, was modestly lower in the fasting state.
2. The hazard ratio (HR) for incident coronary events per 40 mg/dL increase in Friedewald LDL-C was 1.28 (95% CI, 1.07–1.55) for fasting vs 1.32 (95% CI, 1.08–1.61) for nonfasting LDL-C levels.
3. In the primary prevention subgroup, the HR for incident coronary events per 40 mg/dL increase in Friedewald LDL-C was 1.37 (95% CI, 1.11–1.69) for fasting and 1.42 (95% CI, 1.13–1.78) for nonfasting LDL-C levels.
4. The HRs associated with fasting vs nonfasting levels were also similar in analyses in which LDL-C was calculated using the Martin-Hopkins equation in place of the Friedewald equation.
5. In other secondary analyses, the HRs associated with fasting vs nonfasting levels were likewise similar for high-density lipoprotein (HDL) cholesterol, total cholesterol, triglycerides, non-HDL cholesterol, and other cholesterol measures for other CVS events, and in different treatment arms in the study.
6. There was an almost 95% concordance for fasting vs nonfasting levels in classifying patients into appropriate CVS disease risk arms.

In summary, fasting and nonfasting lipid levels yielded almost identical results in this prospective evaluation of CVS event risk in elderly, overweight adults who were followed for approximately 3 years. These findings suggest that it matters little whether fasting or nonfasting lipid levels are examined for the assessment of CVS risk and for the initiation of lipid-lowering therapy for prevention, including primary prevention, of CVS events.

PARTING NOTES

The suggestion to accept nonfasting lipid levels is not new[3]; however, this[2] is perhaps the first study to evaluate the association between fasting vs nonfasting lipid levels on hard CVS outcomes in the same patients.

The use of nonfasting lipid levels for the initiation of lipid-lowering treatment in primary and secondary prevention has been endorsed by the American College of Cardiology, the American Heart Association, and other organizations.[4] *A word of caution: if the patient has had a meal, the clinician must confirm that the meal was not high in fat content because such a meal could result in falsely high-lipid levels.* Finally, what is stated here applies to lipid profile estimation for the general management of dyslipidemia; if the reason for obtaining a lipid profile is different, a fasting profile may be necessary.[5]

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Conflicts of interest
There are no conflicts of interest.

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