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Enhancing Functional Independence Through Modified Adaptation in Progressive Supranuclear Palsy: A Case Report

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Abstract

BACKGROUND & RATIONALE: Progressive supranuclear palsy is a rare neurodegenerative disorder, typically presenting between 60–70 years of age with Richardson's Syndrome as a classical syndrome in PSP. Globally, PSP is estimated to occur at an incidence of 1 per 100,000. PSP is characterised by postural instability and abnormal postures of the limbs, neck, and trunk. Apart from motor impairments, individuals also experience oro-motor difficulties and psychosocial problems. Oro-motor dysfunction interferes with eating, swallowing, and communication. These impairments altogether lead to dependent sitting, poor posture, resulting in ADL dependency, which significantly compromises Quality of life and increases the Caregiver burden.

OBJECTIVES:. To evaluate the impact of customised seating adaptations and assistive device implementation on postural alignment, functional independence in basic ADLs, quality-of-life outcomes, and caregiver burden.

METHODOLOGY: A 58-year-old patient with PSP, bedridden despite multidisciplinary interventions, presented with complete dependence, loss of self-esteem, and increased caregiver burden, which was a great challenge for occupational therapy. A client-centred approach over an 8-week occupational therapy program with customised adaptations was introduced to support posture, self-help skills, and oromotor problems. Outcome measures included the **Functional Independence Measure**, **Progressive Supranuclear Palsy Rating Scale**, **WHO-QOL BREF, Zarit Caregiver Burden Scale , and Canadian Occupational Performance Measure.**

RESULTS: The patient demonstrated marked improvements in posture, independence in ADL, and oromotor functioning, which collectively enhanced QOL. FIM scores improved, PSP-RS scores declined, while WHO-QOL BREF scores indicated reduced caregiver burden, restoring the self-esteem of the patient.

CONCLUSION: Modified sitting adaptations can be an effective occupational therapy stratergy to improve abnormal postures in PSP. This case highlights how individualised assistive technologies and interventions can improve independence, reduce caregiver burden, and enhance quality of life in patients with advanced PSP.

KEYWORDS*:* activities of daily living, modified adaptation, progressive supranuclear palsy.

Introduction

Adaptive customised seating plays a crucial role in providing postural support and positioning, enabling patients to function at their optimal capacity. Such modifications may involve self-help devices, assistive technologies, and environmental adaptations, each tailored to enhance comfort, alignment, and overall performance.(1)

Progressive Supranuclear Palsy (PSP) is a rare neurodegenerative disorder, reported with a global incidence of approximately 1 per 100,000 people and a prevalence of nearly 5 per 100,000. Within the spectrum of clinical variants, PSP-Richardson's syndrome remains the most frequently identified phenotype, with symptoms typically emerging around the age of 64 years. Other phenotypic subtypes, though less common, are also documented.(2) PSP is observed more commonly in males than in females. This is the first documented case demonstrating the use of adaptive customised seating in PSP, which successfully contributed to improved postural stability and better body alignment. An adaptive seating system should provide stable support to the head, trunk, pelvis, upper and lower limbs while ensuring optimal soft-tissue loading to facilitate pressure redistribution.(1) Incorporating assistive technology further helps manage involuntary movements, allowing the individual to participate in day to day activities and manage involuntary movements.

This success was made possible through a collaborative, iterative design approach where Occupational therapist plays a major role in the team to make it clinically effective and practically functional.

The rationale of this study is to evaluate the integrated impact of adaptive customised seating along with assistive technologies, therapeutic techniques, and environmental modifications. We propose that this multidimensional approach can significantly improve activities of daily living, enhance quality of life, and subsequently reduce caregiver burden.

Patient Information

A 58-year-old female with Progressive Supranuclear Palsy (PSP) was referred to the Occupational Therapy Department at AIIPMR, Mumbai, with severe difficulty in sitting and performing daily activities. She arrived in a ordinary manual wheelchair, presenting with normal tone in both upper limbs and increased extensor tone in the right lower limb. Her condition was marked by poor postural control, dysphagia, abnormal trunk–limb postures, and frequent wheelchair falls.

The caregiver reported a gradual functional decline over eight years, with fractures in 2017 and 2021, recurrent freezing episodes, reduced mobility, and increasing emotional distress. Despite multiple previous interventions, she progressed to near-complete ADL dependence, significantly impacting her quality of life and increasing caregiver strain.

Initial assessment using the Functional Independence Measure (FIM**)** revealed total dependence in basic ADLs. The Canadian Occupational Performance Measure (COPM) reflected low performance and satisfaction across self-care, productivity, and leisure domains, highlighting an urgent need for individualised occupational therapy intervention.

Clinical Findings

She presented with axial rigidity, retrocollis, neck hyperextension–lateral flexion, elevated–retracted scapulae, adducted/internally rotated shoulders, right hip–knee flexion, and foot inversion.

Motor exam showed normal tone in both upper limbs but increased extensor tone in the right lower limb, with voluntary control fair–right/ fair+ left in ULs, synergy in right LL, fair+ left LL, Rt hand function

was poor, whereas left was fair, impaired coordination, and marked bradykinesia–akinesia. For coming to sit from bed, she requires attendant assistance**,** with a tendency for back extension**.** She was totally dependent for ADLs, including feeding, grooming, dressing, toileting, and transfers.

Timeline- Patient visited as outpatient on a follow–up basis for therapeutic interventions, wheelchair prescription and customised modified seating adaptation and ADL training with assistive device and techniques for 8 weeks**.**

Diagnostic Assessment MRI report depicted Richardson syndrome with mild flattening of the superior margin of midbrain with mild atrophy along with bipyramidal, cerebellar and extrapyramidal dysfunction. Lab findings – MRI Findings done in 2020 reveal the possibility of progressive supranuclear palsy . The decrease in the midbrain and pons ratio is more favorable for MSA-P.

Therapeutic Intervention

Following a customised seating intervention, she was able to maintain an upright, comfortable sitting posture for longer durations without sliding (S1), with improved head control in neutral for functional gaze during daily activities at home (S2–S3). Within three weeks, her sitting endurance increased progressively, enabling approximately 6–8 hours of supported upright sitting with adequate postural stability (T2). By Week 3, she could consume soft, easily chewable foods more efficiently (M1), and by Week 5, she initiated simple seated leisure tasks (M2). Her son and husband assisted with feeding, positioning, and providing required materials for leisure and basic household involvement (A1–A3). Progress in occupational performance and satisfaction was monitored using the COPM (R1–R2), reflecting gradual improvement in participation and daily engagement.

Table 01 : Problem Intervention Outcome Table

S. no	Time interval	Identified Problem	Intervention / Prescription	Outcome/ Achievement
1.	1st week	Came in an ordinary wheelchair without modifications; checkout revealed it to be inappropriate.	Prescribed standard adult reclining wheelchair.	
2.	2nd week	Poor sitting endurance, incorrect posture, leading to discomfort and sliding	Reclining wheelchair evaluated — further customisation needed.	Sitting and comfort still not achieved.
3.	2nd week	Uncontrolled involuntary upper & lower limb movements	High backrest, lateral head support & straps were provided.	Improved trunk stability and neck alignment achieved.
4.	2nd week	Sliding on an ordinary cushion.	Footrest height adjusted.	Still inadequate support noted.
5.	3rd week	Foot not resting on footrest Persistent poor foot support.	Extended detachable padded footrest with straps prescribed.	Feet aligned and well supported.

6.	3rd week	Involuntary upper limb movements causing risk of hand injury; unable to use hands for ADLs.	Lapboard prescribed.	Arms rested at 90°; enable tabletop activities and improved ADL participation.
7.	3rd week	Right lower limb dystonic movements causing knee hyperextension and pain.	Wooden calf support given	Reduced knee extension and controlled dystonic movements
8.	4th week	Involuntary distal movements hindering hand-to-mouth feeding.	Built-up handle + 500g weighted cuff prescribed.	Reduced involuntary movement → easier self-feeding.
9.	4th week	Difficulty scooping food, leading to spillage.	Plate guards + non-slip mats prescribed.	Scooping improved and spillage reduced.
10.	4th week	Difficulty swallowing solid foods.	Food texture modification: liquified → pureed → minced & moist → soft bite size → easy to chew → regular; seat at 90°(7).	Swallowing became easier with posture & diet modification.
11.	5th week	Dressing completely dependent on the caregiver.	Forward chin tuck dressing technique taught; front opening garments, Velcro/magnetic closures + reacher suggested(10)	Dressing simplified; assistance required reduced to minimal.
12.	5th week	Difficulty in writing was noted.	Weighted pens along with a slanting board were provided.	Reduced involuntary movement and promoted correct posture
13.	5th week	Difficulty with transfers due to rigidity	Safe transfer training given to caregiver: bottom forward, feet positioned, hands placed, chin forward & up; taught chair/bed transfers; bed stick advised.	Safe transfers are performed effectively by the caregiver.
14.	6th week	Risk of toilet-related falls.	Toilet modifications: freestanding toilet, grab bars, non-slip mats (10).	Reduced fall risk & improved toilet safety.
15.	7th week	The home environment is unsafe for mobility.	Removal of small rugs, a doorway width of 32” was suggested. The arrangement of furniture was explained.	Increased safety and smooth wheelchair access.
16.	8th week	Difficulty socialising & communicating.	Eye-tracking augmentative device was introduced; Talkitt app installed; communication	App converted dysarthric speech to intelligible form;

			board recommended; environmental control + feather-touch switches with 20" height.	improved communication & social engagement.

The patient was previously asked to sit on the wheelchair for 1-2 hours/day and gradually increase the time duration. The patient now sits on the adaptive seating for about 3-8 hrs. (8)

Table 02: Shows Pre and Post Intervention Scores

Outcome Measure	Pre – Intervention score	Post Intervention Score	Duration of Intervention
FIM (Self – Care)	10/42	25/42	8 weeks
PSP-RS	57/100	32/100	8 weeks
COPM- Performance	5/50	26/50	8 weeks
COPM- Satisfaction	3/50	28/50	8 weeks
WHO-QOL-BREF	66/100	92/100	8 weeks
ZARIT – Caregiver Burden Scale	68/88	31/88	8weeks

Graphical Presentation of FIM

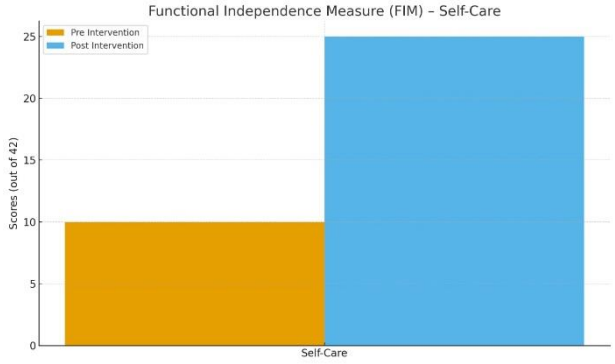

Table 3

Graphical Presentation of COPM

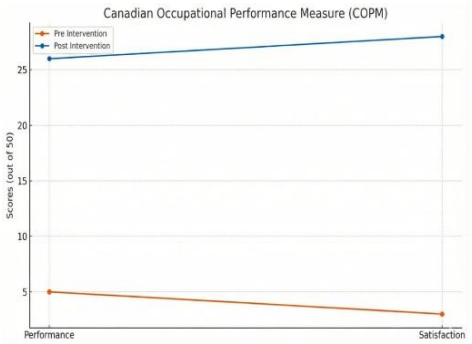

Table 4

Graphical Representation of Progressive Supranuclear Palsy

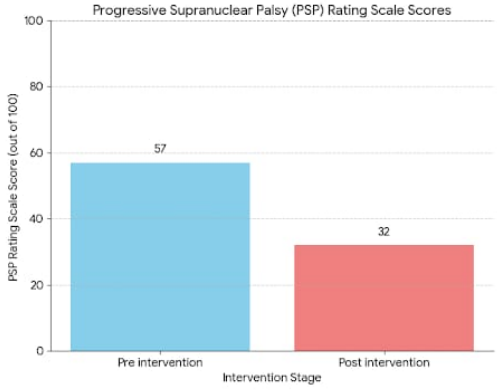

Table 5

Graphical Representation of WHOQOL- BRIEF

Table 6

Graphical Representation of Zarit Caregiver Burden Scale

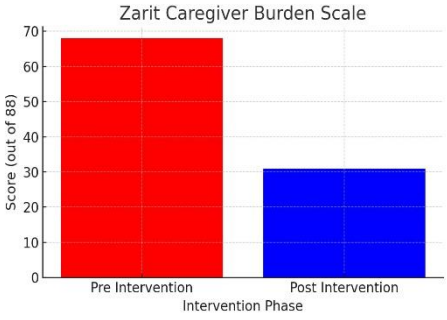

Table 7

Discussion

This case highlights the effectiveness of a client-centred, low-cost Occupational Therapy intervention in improving function and participation in an adult with Progressive Supranuclear Palsy (PSP). At baseline, the patient lacked an appropriate mobility system and was unable to sustain a functional sitting posture. Following occupational therapy assessment, her ordinary wheelchair was discontinued and replaced with a reclining wheelchair with customised adaptive seating**,** facilitating postural alignment, stability, comfort and improved participation across daily living domains.

Literature emphasises that an optimally supported seating system provides the stable proximal base required for distal motor control and purposeful engagement (4). As outlined in the Human Activity Assistive Technology (HAAT) Model, seating and wheelchair systems function as extrinsic enablers, shaping occupational performance by supporting interaction between the individual, task and environment (1).

Across 8 weeks, systematic modifications including high-back support, lateral head control, anterior wedge cushion, lapboard, padded footrest with straps, calf support and shoulder harness effectively reduced dyskinetic overflow, improved pelvic positioning, enhanced trunk alignment and enabled productive tabletop participation. Weighted cuffs, built-up utensils, non-slip mats and plate guards further improved self-feeding efficiency, while AAC support (Talkitt application) enhanced communication and reduced caregiver dependency(10).

Outcome measures demonstrated significant improvement, with FIM–Self Care scores increasing from 10 to 25, COPM Performance from 5 to 26, COPM Satisfaction from 3 to 28, WHO-QOL BREF from 66/100 to 92/100, and the Zarit Caregiver Burden Scale decreasing from 68/88 to 31/88, indicating a marked reduction in caregiver strain. These results align with growing evidence on the value of assistive technology and Occupational Therapy-guided seating interventions in PSP, affirming that functional participation does not rely on high-cost solutions**,** but on clinical reasoning, individualised design and user-training(9). In this case, Occupational Therapy-driven assistive technology became the platform for independence—bridging severe motor impairment with meaningful engagement in feeding, communication, grooming, and daily routine. Low-cost customisation therefore emerged as the cornerstone of the patient's progress, improving quality of life while reducing caregiver strain. Patient's Perspective – From the patient's perspective, she expresses satisfaction with the OT intervention, which enhanced comfort, mobility, and participation in meaningful occupations.

Conclusion

The outcomes reinforce that it is not technological sophistication but the Occupational Therapist's assessing the priorities' of patient ,clinical reasoning, customisation, and training that transform assistive devices into functional enablers. This case illustrates that targeted seating intervention and adaptive strategies can bridge severe motor impairment to meaningful everyday participation while reducing caregiver strain.

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