



REFRAMING PARTICIPATION: AN INTEGRATED OCCUPATIONAL THERAPY APPROACH – A CASE REPORT

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ABSTRACT

Occupation-centred care is central to Occupational Therapy, prioritizing meaningful engagement and participation over symptom-focused management. The case describes a 3-year-old child diagnosed with Autism Spectrum Disorder and a background of VACTERL association. Assessment using OTPF-4, COPM, Sensory Profile and clinical observations identified key occupational challenges in play, feeding, and social engagement. Intervention integrated Ayres Sensory Integration for regulation, graded sensory-behavioural feeding strategies, structured mealtimes, and caregiver coaching. Clinically meaningful improvements were seen in regulation, food acceptance, engagement, and participation. This case demonstrates how occupation-centred care, grounded in meaningful daily activities, facilitates holistic development and participation in children with neurodevelopmental challenges by reinforcing the core essence of Occupational Therapy—enabling occupation as a medium for growth, independence, and well-being.

KEYWORDS : Occupation-Centred Practice; Participation; Integrated Approach; VACTERL Anomaly; Early Childhood

INTRODUCTION

Autism Spectrum Disorder (ASD) is a significant and growing neurodevelopmental condition characterized by persistent difficulties in social communication and restricted/repetitive behaviors, with global rates showing an upward trend influenced by better awareness and wider diagnostic practices. In India, community-based and regional studies report varying prevalence estimates—ranging from approximately 0.15% of children aged 1–10 years (Raina SK, Chander V, et al. 2017). Children with major congenital anomalies often face neurodevelopmental challenges beyond their primary physical conditions, and while research is limited, multiple studies have linked multiple congenital anomalies, low birth weight, repeated surgical procedures, and prolonged hospital stays in infancy to later neurodevelopmental dysfunctions (Kassa AM, Dahl M, et al. 2020). In the context of rare multisystem conditions like VACTERL association—defined by at least three malformations such as vertebral anomalies, anal atresia, cardiac defects, tracheoesophageal fistula, renal anomalies, and limb abnormalities—most affected infants require surgery in the first days of life and often undergo repeated anaesthetic exposures (Kassa AM, Lilja HE, et al. 2023). While literature is scarce, recent population-based cohort evidence shows that individuals with VACTERL association have a significantly increased risk of being diagnosed with neurodevelopmental disorders including ADHD, ASD, and intellectual disability compared to matched controls (e.g., 5-fold higher risk for ASD) (Kassa AM, Lilja HE, et al. 2023) underscoring the need for long-term developmental surveillance and early intervention. Hence, this case report aims to demonstrate the effectiveness of an integrated, occupation-centred occupational therapy approach in improving regulation, feeding behaviours, and participation in a 3-year-old child with Autism Spectrum Disorder, with a background of VACTERL association, highlighting the role of early, holistic OT intervention in medically complex children.

Case Study

This is a 3 year old male child, born out of a non-consanguineous marriage. The mother's age at the time of pregnancy was 27 years with a history of bleeding and hypertension during the first trimester. The child was delivered at full term, LSCS, cried immediately after birth, with birth weight – 3.25 kg. The child has a significant medical history of VACTERL anomaly.

Surgical history of –

- 1) Tracheoesophageal fistula repair – 2nd day of life

- 2) Anorectoplasty- stoma attached – 2 months old
- 3) Rectobulbar fistula- tongue tie repair
- 4) Suggestive of Tethered cord syndrome management

The child presented with poor eye contact, inconsistent response to name, reduced sitting tolerance, inattention, distractibility, and limited age-appropriate social interaction and communication skills.

Feeding concerns included selective food acceptance, with marked avoidance of soft food textures. Motor and speech milestones were delayed. Visual and auditory localization and discrimination skills were present but inconsistent. The child demonstrated understanding of basic shapes and colours and exhibited age-appropriate gross and fine motor abilities. Play behaviour was predominantly repetitive and solitary, characterized by throwing toys and objects rather than engaging in purposeful or reciprocal play.

Deficits in performance areas- Play participation, feeding participation and social engagement.

METHODOLOGY

Assessment was guided by the Occupational Therapy Practice Framework-4th Edition (AOTA, 2020). Standardized tools included the

- Indian Scale for Assessment of Autism (ISAA) - Used to determine the severity of autistic features. The child's score indicated mild autism.
- Sensory Profile- Administered to evaluate sensory processing patterns. Findings revealed difficulties across multiple quadrants, including sensory sensitivity, sensory seeking, low registration, and sensory avoidance, indicating challenges in modulation and response to sensory input.

Outcome measures used included the

- Brief Autism Mealtime Behavior Inventory (BAMBI) - to evaluate mealtime behaviors and feeding challenges
- Canadian Occupational Performance Measure (COPM) - to capture caregiver-perceived changes in the child's occupational performance and satisfaction across priority areas.

Intervention

Intervention mainly focussed on –

An integrated, occupation-centered intervention framework was adopted, grounded in principles of Ayres Sensory

Integration (ASI), behavioral feeding hierarchy, structured routines, and caregiver coaching. Sessions were conducted in a child-friendly therapeutic environment with strong emphasis on engagement and intrinsic motivation.

➤ Sensory Integration-Based Intervention to Enhance Play and Social Skills

Caregiver coaching emphasized evidence-based strategies such as modelling, shared affect, and supported engagement (Wong et al., 2015). Sensory preparation was incorporated prior to seated activities through proprioceptive and deep-pressure input to support regulation and readiness for engagement (Schaaf et al., 2015). Environmental structuring strategies included brief, clear instructions to support working memory and task initiation, alongside structured practice to strengthen execution and consistency (Karalunas et al., 2017).

Participation was supported through reinforcement systems and praise to reduce task avoidance and sustain motivation. Seated turn-taking routines were embedded within daily activities to enhance joint attention and social reciprocity, while peer interaction opportunities were incorporated to promote shared attention, cooperative engagement, and functional social participation.

➤ Feeding Intervention

Coaching focused on establishing sensory-based feeding routines with behavioral reinforcement to gradually shape food acceptance.

Parents were educated on the Hierarchical Food Acceptance Scale to structure graded exposure, reduce defensiveness, and align stepwise reinforcement strategies with the child's progression (Koegel et al., 2012). Psychoeducation addressed sensory processing and oral defensiveness, linking the child's sensory profile to feeding behaviors, while incorporating proprioceptive and vestibular input prior to meals to enhance regulation and readiness (Dunn et al., 2016). Intervention incorporated structured mealtime sessions, sensory-feeding play activities (touching, mashing, licking, biting) to support desensitization, and positive reinforcement to decrease selectivity and increase willingness to engage with new textures (Hasselby). These strategies were consistent with evidence underscoring the influence of caregiver practices and mealtime environments on feeding participation (Benjasuwantep et al., 2013).

Intervention was provided for 3 months through twice-weekly therapy sessions, with regular monitoring of goals and progress.

Findings and Analysis

Pre- and post-intervention analysis of outcome measures revealed clinically meaningful improvements in targeted occupational performance areas.

Table 1- Pre- and Post-intervention Analysis of Outcome Measures

	Pre- intervention	Post- intervention
BAMBI	44	31
COPM	2.7	6.7

Following intervention the Brief Autism Mealtime Behavior Inventory (BAMBI) score decreased from 44 at baseline to 31 following intervention, indicating a reduction in feeding-related maladaptive behaviors and improved mealtime participation.

The Canadian Occupational Performance Measure (COPM) revealed a substantial increase in mean scores from 2.7 pre-intervention to 6.7 post-intervention, reflecting enhanced occupational performance and caregiver satisfaction in targeted domains.

DISCUSSION

An important clinical consideration in this case is the child's history of VACTERL anomaly and the multiple major surgeries undertaken during the neonatal and early infancy period. While the child later presented with sensory modulation difficulties, limited regulation, feeding challenges, and reduced participation—features often associated with Autism Spectrum Disorder—it is essential to recognize that early medical experiences may have also significantly contributed to these difficulties. Infants who undergo repeated invasive procedures, prolonged hospitalization, NICU exposure, and early life medical stress frequently may experience altered sensory processing, disrupted co-regulation opportunities, reduced proprioceptive and tactile security, and heightened defensiveness due to persistent noxious input and limited positive sensory experiences (Pineda, R. G., Neil, J. et al. 2014). Moreover, early surgical interventions and prolonged medical stressors have been associated with subsequent behavioural and cognitive difficulties (Kassa & Dahl, 2020; Kassa & Lilja, 2023). Feeding experiences in children with medical complexity, including those with VACTERL association, are often associated with persistent swallowing and feeding difficulties that negatively impact mealtime participation and quality of life (Bergmann et al., 2023). In this context, the child's presentation cannot be viewed merely as a consequence of autism, but rather as the cumulative outcome of neurodevelopmental vulnerability compounded by early adverse sensory experiences. This reinforces the critical role of occupational therapy from the earliest stages of life, particularly for medically complex infants such as those with VACTERL association. Early occupational therapy involvement in NICU and infancy can support regulation, positive sensory exposure, parent-infant bonding, feeding readiness, environmental modification, and developmental stability—potentially mitigating later participation challenges.

CONCLUSIONS

This case demonstrates how an integrated, occupation-centered occupational therapy approach can meaningfully enhance a child's regulation, feeding participation, social engagement, and overall functional involvement in daily routines. Through structured intervention, caregiver partnership, and supportive environmental adaptations, the child was able to achieve clinically relevant, functional gains that translated into improved participation.

Importantly, this case also highlights the need to situate a child's current occupational performance within the context of their early medical history. For children with conditions such as VACTERL association, prolonged hospitalization, multiple surgeries, and early adverse sensory experiences may shape regulation, sensory processing, and participation trajectories. Recognizing this interconnected developmental pathway strengthens the argument for early, proactive occupational therapy involvement beginning in the NICU and continuing as a developmental continuum of care.

This perspective underscores the value of occupational therapy as a continuum of care, beginning at birth and extending through childhood to support participation, well-being, and quality of life in medically complex children.

Recommendations:

• Early Occupational Therapy Involvement

Occupational therapy should be integrated as a part of routine care for medically complex infants, especially those with VACTERL association, NICU experiences, prolonged hospitalization, or multiple early surgeries, to support regulation, sensory stability, and developmental continuity.

• Participation-Focused Pediatric Care

Interventions should move beyond symptom management to emphasize participation in meaningful occupations—

feeding, play, social engagement, and family routines— as central therapeutic outcomes.

- **Interdisciplinary Coordination**

Close collaboration between pediatric surgeons, neonatologists, developmental pediatricians, psychologists, and occupational therapists is essential to address the complex sensory, behavioral, and functional needs of children with VACTERL or similar medical conditions.

- **Further Research and Documentation**

There is a need for more clinical studies exploring the relationship between early surgical/medical experiences and later sensory processing and participation outcomes, as well as documenting the long-term impact of early OT involvement in such populations

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