

# PAEDIATRIC ACUTE-ONSET NEUROPSYCHIATRIC SYNDROME (PANS) & OCCUPATIONAL PERFORMANCE: WHAT DO WE KNOW SO FAR?

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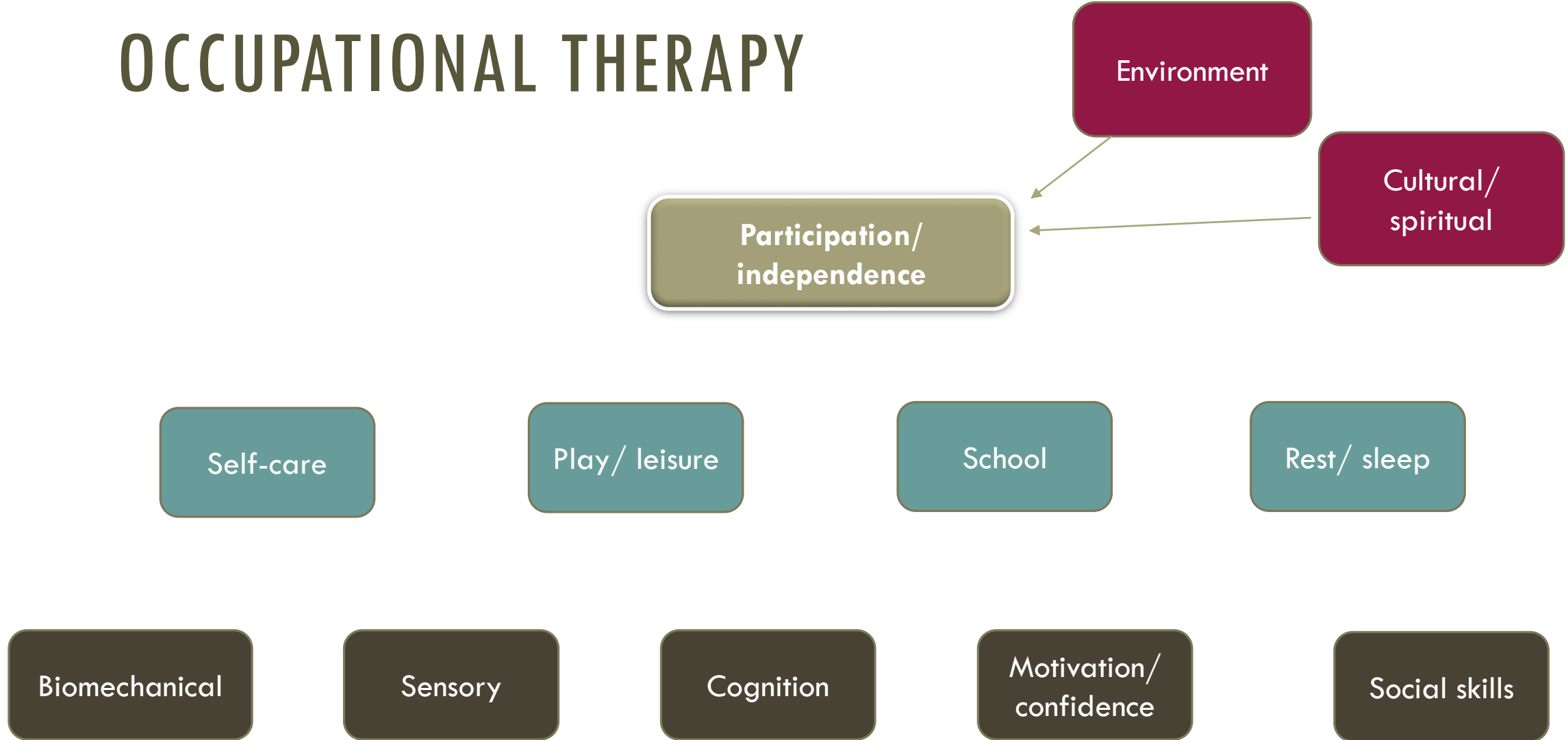
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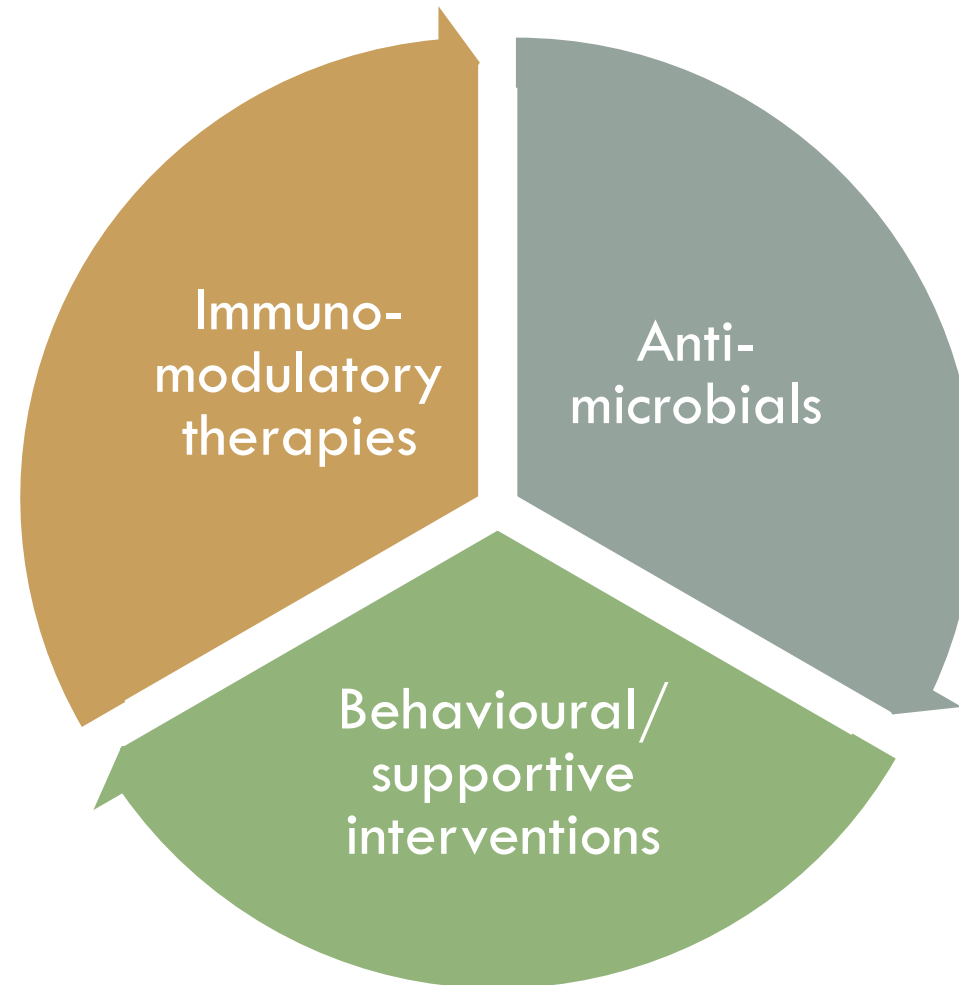
Associate Professor Janice Tona, Occupational Therapy Program Director, University at Buffalo, NY, USA.

# OCCUPATIONAL THERAPY



(Adapted from Chapparo & Ranka, 1997)

# OCCUPATIONAL THERAPY: PANS/ PANDAS



Adapted from Swedo et al 2017

# RESEARCH QUESTION

What is currently known about the relationship between PANS and occupational performance?

# STUDY DESIGN

## Scoping review

- Map current literature examining link between PANS & occupational performance

## Scoping review framework<sup>1</sup>

- Define broad question
- Clearly define study parameters
  - Concept being studied
  - Target population
  - Specific outcomes of interest

(<sup>1</sup>Levac et al, 2010)

# IDENTIFYING RELEVANT STUDIES: SEARCH TERMS

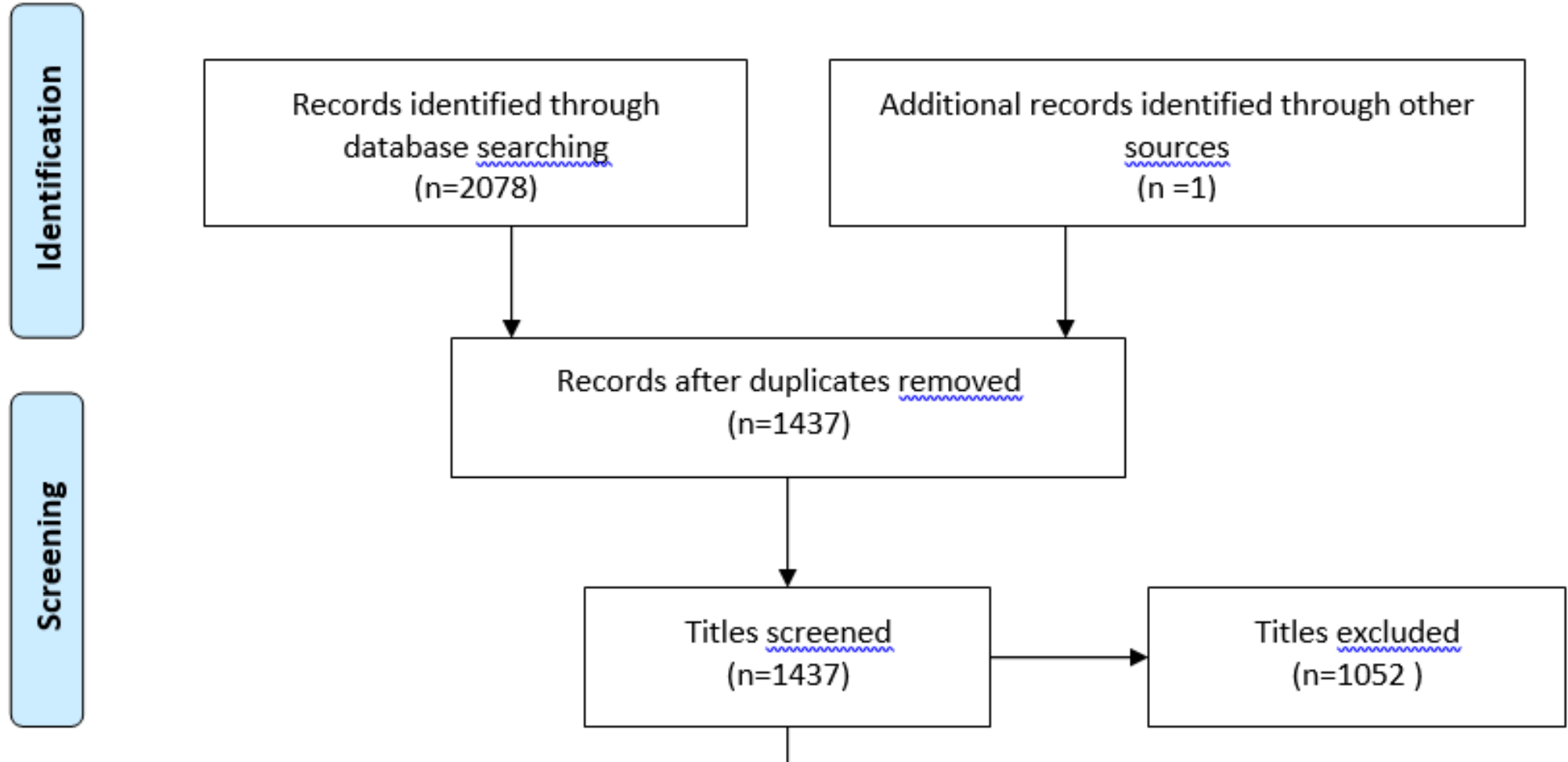
<b>Concept/ Diagnostic group</b>	<b>Population</b>	<b>Occupational performance outcomes</b>
<p>PANS; Paediatric Acute on-set Neuropsychiatric Syndrome; PANDAS; Paediatric autoimmune neuropsychiatric disorder associated with Streptococcal infections; CANS; Childhood Acute Neuropsychiatric Syndrome; PITAND; Paediatric Infection Triggered Autoimmune Neuropsychiatric Disorder.</p>	<p>Teen; Youth; Adolescent; Juvenile; Child; Infant; Baby; Babies; Paediatric.</p>	<p>Activities of Daily Living; Bathing; Showering; Dressing; Swallowing; Feeding; Eating disorders; Food restriction; Oral-motor; Mobility; Mobility limitation; Personal hygiene; Grooming; Communication; Handwriting; Computer use; Household management; Chores; Religious participation; Religious expression; Rest; Relaxation; Sleep; Sleep wake disorders; School; Play; Leisure; Social participation; Occupation; Occupational performance ; Occupational engagement; Fine motor skills; Gross motor skills; Visual spatial skills; Visual perception; Sensory.</p>

# DATABASES SEARCHED

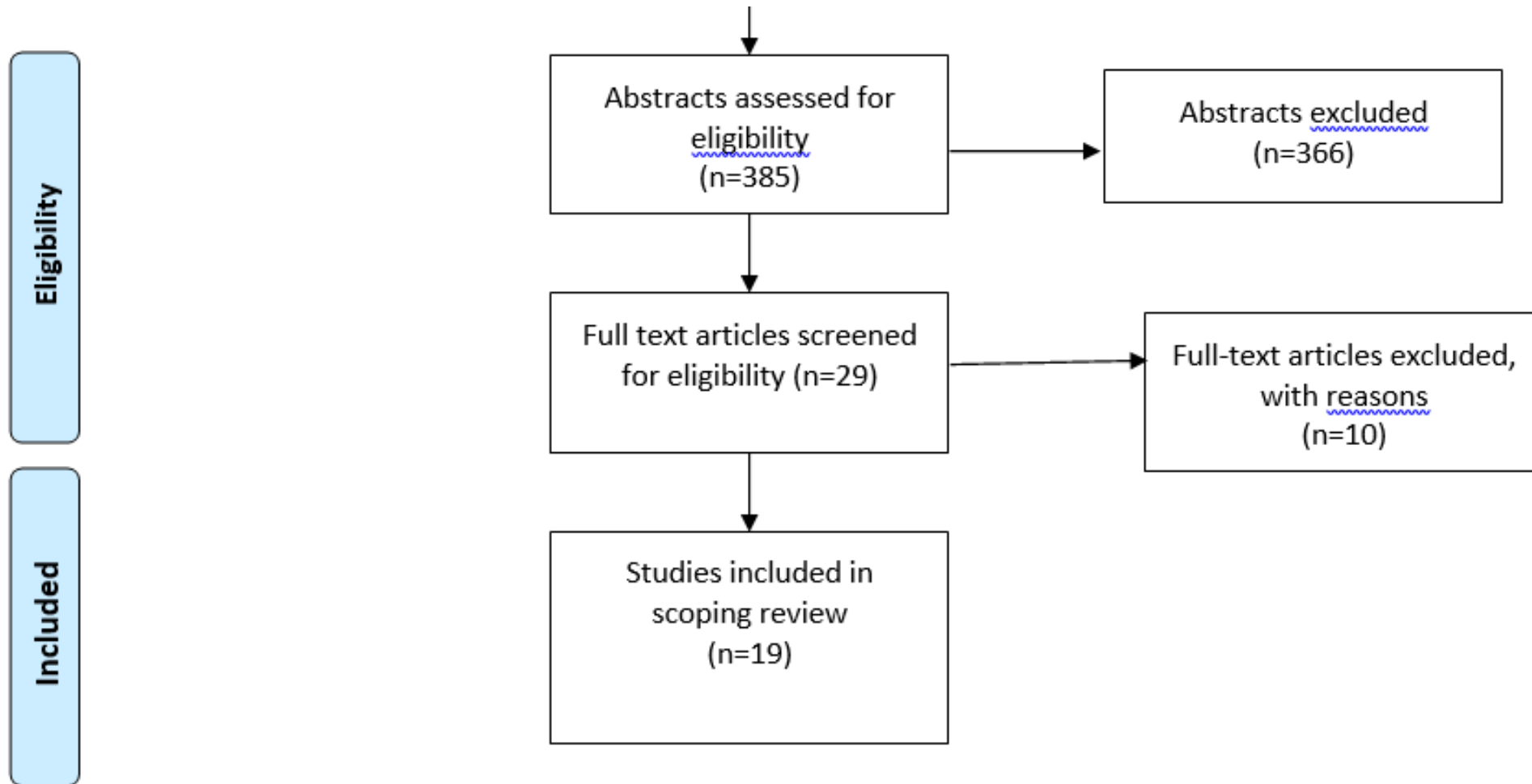
1. EMBASE – biomedical and pharmacological
2. MEDLINE – life sciences and biomedical
3. CINAHL – nursing, allied health, biomedicine and healthcare
4. Cochrane – Systematic reviews
5. PsycInfo – Psychology
6. SCOPUS – life sciences, social sciences, physical sciences and health sciences
7. ERIC – Education Resources Information Center



# PRISMA FLOW DIAGRAM



# PRISMA FLOW DIAGRAM



# DATA EXTRACTION

Author(s) and year of publication

Journal

Diagnosis

Participant ages

Inclusion/ exclusion

Remission/ Exacerbation/  
Not specified

Study design & features

Outcome Measure

Author conclusions

Study limitations

# THEMATIC ANALYSIS

Approach guided by Braun & Clarke (2006)

Deductive approach based on Occupational Performance Model (Australia) <sup>1</sup>

- Occupational Performance Areas
- Occupational Performance Components

(<sup>1</sup>Chapparo & Ranka, 1997)

# THEMATIC ANALYSIS

Approach guided by Braun & Clarke (2006)

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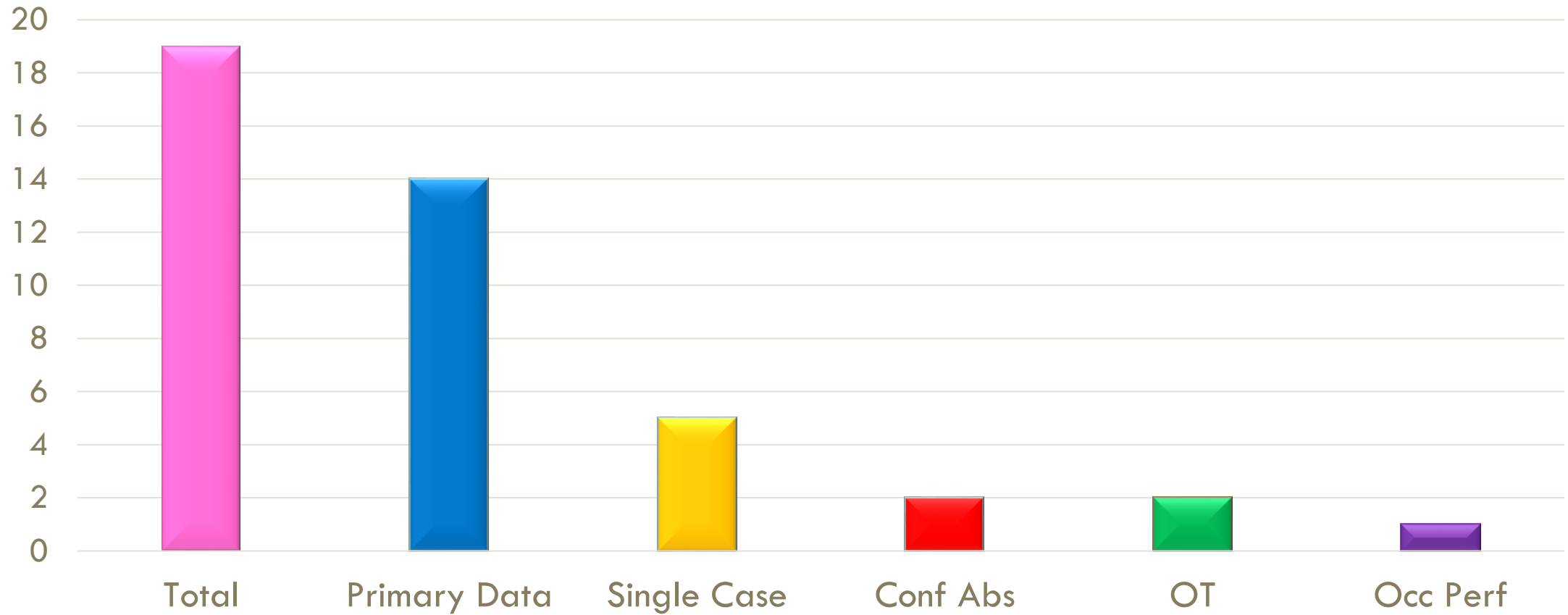
## Inductive

- Looking for patterns within Occupational Performance Areas & Components

(<sup>1</sup>Chapparo & Ranka, 1997)

# DATA EXTRACTION

## Preliminary Findings



# THEMATIC ANALYSIS: PERFORMANCE AREAS

## *PRELIMINARY FINDINGS*

### Productivity

- School
- Handwriting
- Homework
- Maths

### Play/ Leisure

- Extra-curricular
- Holiday Camp

### Self-Maintenance

- Eating
- Dressing
- Toileting
- Personal hygiene/grooming

### Rest/ Sleep

- Sleep
- Bedtime fears
- Relaxation

# THEMATIC ANALYSIS: PERFORMANCE COMPONENTS

## *PRELIMINARY FINDINGS*

### Bio-mechanical

- Elimination
- Fine motor
- Gross motor
- Pain
- Unusual movements
- Weakness/ fatigue

### Cognitive

- Academic performance
- Executive function
- Visual perception

### Sensory-Motor

- Sensory processing
- Hyperactivity

### Inter-personal

- Aggression/ rage
- Communication
- Anxiety (separation)
- Oppositional behaviours
- Social/ peer participation

### Intra-personal

- Mood
- Anxiety/ irrational fears
- Behaviour changes
- Insight
- Self regulation
- Social withdrawal
- Psychosis/ self harm



# DISCUSSION

PANS exacerbations pervasive

All occupational performance areas affected

All occupational performance components affected

# DISCUSSION

Paucity of Occupational Therapy specific publications

Paucity of primary source data examining occupational performance in PANS population (1/14)

Current research gaps:

- Standardised measures of occupational performance areas & components
- Performance comparisons during and between exacerbations

# CONCLUSION

Given the impact across all occupational performance areas, Occupational Therapy has a role in supporting children with PANS

More rigorous research is needed to examine the occupational performance challenges in this population to guide practice in this population

# NEXT STEPS

What are the differences in occupational performance in children with PANS, during versus between exacerbations?

What are the differences in sensory processing in children with PANS, during versus between exacerbations?

# NEXT STEPS

What are the differences in occupational performance in children with PANS, during versus between exacerbations?

What are the differences in sensory processing in children with PANS, during versus between exacerbations?

# NEXT STEPS

## Vineland Adaptive Behavior Scale 3

- Daily living skills
- Socialization
- Communication



## Sensory Processing Measure:

- Vision
- Hearing
- Touch
- Body awareness
- Balance & motion

# REFERENCES

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Chapparo, C. & Ranka, J. (1997). *Occupational Performance Model (Australia): Monograph 1*. The University of Sydney: OP Network.

Cutforth T., DeMille MMC., Agalliu I. and Agalliu D. (2016). CNS autoimmune disease after Streptococcus pyogenes infections: animal models, cellular mechanisms and genetic factors. *Future Neurology*: 10.2217/fnl.16.4.

Doran, P. (2016). What are PANDAS and PANS and why do educators need to know? In P. Doran (Ed.), *PANDAS and PANS in school settings: A handbook for educators*. Philadelphia: Jessica Kingsley.

Frankovich, J., Swedo, S. E., Murphy, T., Dale, R. C., Agalliu, D., Williams, K., Daines, M., Hornig, M., Chugani, H., Sanger, T., Muscal, E., Pasternack, M., Cooperstock, M., Gans, H., Zhang, Y., Cunningham, M., Bernstein, G., Bromberg, R., Willett, T., Brown, K., Farhadian, B., Chang, K., Geller, D., Hernandez, J., Sherr, J., Shaw, R., Latimer, E., Leckman, J., Thienemann, M. (2017). Clinical management of pediatric acute-onset neuropsychiatric syndrome: Part II-use of immunomodulatory therapies. *Journal of Child and Adolescent Psychopharmacology*, 27(7), 574-593.

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5, 69-77. doi:10.1186/1748-5908-5-69

Swedo, S. E., Leckman, J.F & Rose, N, R. (2012). From research subgroup to clinical syndrome: modifying the PANDAS criteria to describe PANS (Pediatric Acute-onset Neuropsychiatric Syndrome). *Pediatrics & Therapeutics*, 2(2). doi:10.4172/2161-0665.1000113

Tona, J., Bhattacharjya, S., & Calaprice, D. (2017). Impact of PANS and PANDAS exacerbations on occupational performance: a mixed-methods study. *American Journal of Occupational Therapy*, 71(3), 1-9. doi:10.5014/ajot.2017.022285

# SCOPING REVIEW: INCLUDED ARTICLES

Bagian, K., & Hartung, S. Q. (2015). Is It PANS, CANS, or PANDAS?: Neuropsychiatric Pediatric Disorders That Are Not Black and White—Implications for the School Nurse. *NASN school nurse*, 30(2), 96-104.

Bernstein, G. A., Victor, A. M., Pipal, A. J., & Williams, K. A. (2010). Comparison of clinical characteristics of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and childhood obsessive-compulsive disorder. *Journal of Child & Adolescent Psychopharmacology*, 20(4), 333-340.

Calaprice, D., Tona, J., Parker-Athill, E. C., & Murphy, T. K. (2017). A survey of pediatric acute-onset neuropsychiatric syndrome characteristics and course. *Journal of Child and Adolescent Psychopharmacology*, 27(7), 607-618.

Chalemian, B. A., Amir, A., & Jadapalie, S. L. K. (2011). A 7-year-old boy with ADHD. *Psychiatric Annals*, 41(5), 249-251.

Doran, P.R. (2015). Sudden behavioral changes in the classroom: What educators need to know about PANDAS and PANS. *Beyond Behavior*, 24(1), 31-37.

Estivill-Domenech, C., Rodriguez-Morilla, B., Aragones, E., Segarra, F., Madrid, J. A., & Estivill, E. (2017). Association between pandas (pediatric autoimmune neuropsychiatric disorder associated with streptococci) and non 24-hours sleep wake disorder. *Sleep Medicine*, 40 (Supplement 1), e91.

Frankovich, J., Thienemann, M., Pearlstein, J., Crable, A., Brown, K., & Chang, K. (2015). Multidisciplinary clinic dedicated to treating youth with pediatric acute-onset neuropsychiatric syndrome: presenting characteristics of the first 47 consecutive patients. *Journal of Child & Adolescent Psychopharmacology*, 25(1), 38-47.



# SCOPING REVIEW: INCLUDED ARTICLES

Gaughan, T., Buckley, A., Hommer, R., Grant, P., Williams, K., Leckman, J. F., & Swedo, S. E. (2016). Rapid Eye Movement Sleep Abnormalities in Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS). *Journal of Clinical Sleep Medicine, 12*(7), 1027-1032. Hirschtritt, M. E., Hammond, C. J., Luckenbaugh, D., Buhle, J., Thurm, A. E., Casey, B., & Swedo, S. E. (2009). Executive and attention functioning among children in the PANDAS subgroup. *Child Neuropsychology, 15*(2), 179-194.

Lewin, A. B., Storch, E. A., Jane Mutch, P., & Murphy, T. K. (2011). Neurocognitive functioning in youth with pediatric autoimmune neuropsychiatric disorders associated with streptococcus. *Journal of Neuropsychiatry and Clinical Neurosciences, 23*(4), 391-398.

Murphy, M. L., & Pichichero, M. E. (2002). Prospective identification and treatment of children with pediatric autoimmune neuropsychiatric disorder associated with group A streptococcal infection (PANDAS). *Archives of Pediatrics & Adolescent Medicine, 156*(4), 356-361.

Murphy, T., Patel, P. D., McGuire, J. F., Kennel, A., Mutch, P. J., Parker-Athill, E. C., . . . Toufexis, M. D. (2014). Clinical characteristics of children with pediatric acute-onset neuropsychiatric syndrome (PANS) phenotype. *Neuropsychopharmacology, 1*), S578.

O'Rourke, K. (2003). PANDAS syndrome in the school setting. *School Nurse News, 20*(4), 34-35.

# SCOPING REVIEW: INCLUDED ARTICLES

Shanker, G., Srivastava, M., & Tripathi, M. N. (2012). Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS): A case report. *Indian Journal of Psychiatry, 1*), S108.

Singh, A., Kumar, T. S., & Padhy, S. K. (2015). PANDAS presenting in a young boy: A case report. *Indian Journal of Psychiatry, 1*), S152-S153.

Swedo, S. E., Leonard, H. L., Garvey, M., Mittleman, B., Allen, A. J., Perlmutter, S., . . . Lougee, L. (1998). Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections: Clinical description of the first 50 cases. *American Journal of Psychiatry, 155*(2), 264-271.

Tona, J., & Posner, T. (2011). Pediatric autoimmune neuropsychiatric disorders. *OT Practice, 16*(20), 14-19.

Tona, J., Bhattacharjya, S., & Calaprice, D. (2017). Impact of PANS and PANDAS Exacerbations on Occupational Performance: A Mixed-Methods Study. *American Journal of Occupational Therapy, 71*(3), 1-9.

Toufexis, M. D., Hommer, R., Gerardi, D. M., Grant, P., Rothschild, L., D'Souza, P., . . . Murphy, T. K. (2015). Disordered eating and food restrictions in children with PANDAS/PANS. *Journal of Child & Adolescent Psychopharmacology, 25*(1), 48-56.

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