Implementing Yoga as an Intervention for Reducing Caretaker

Burnout in Caregivers of the Autism Spectrum Disorder Community on the North Shore of Staten Island

> Adedayo Adebo - WCSN, Megan Chiu - WCSN Wagner College Evelyn L Spiro School of Nursing



Autism spectrum disorder (ASD) refers to a broad range of developmental disabilities that affect social skills, repetitive behaviors, speech and nonverbal communication.

There is an increasing prevalence of autism, but a decreased level of support, guidance, and education being offered. NYS made recent budget cuts to Medicaid and funding for essential organizations like the Office of People with Developmental Disabilities and Eden 2 School. (1)

Caregivers of people with ASD may experience high levels of stress from providing care without additional support that may have negative physiological and psychological effects on caregivers such as fatigue, lowered immunity, and depression (2). This is how caretaker burnout develops.

Yoga can provide relief for caregivers so they do not experience burnout or can alleviate symptoms of caretaker burnout. Research on the benefits of yoga have been shown to enhance bonding and renewal of familial relationships and improve gross and fine motor functioning skills. (3, 4)

Community Assessment & Analysis North Shore of Staten Island (5,6):

Population:

~175,000 people; 51% female, 49% are male

Age:

23% = under the age of 18 13% = over the age of 65 31% = over the age of 25 that has a Bachelor's degree

Financial hardship and instability: 21% live under the poverty line Over 35% experience rent burden (uses 35% or more of their income on rent)

Ethnicity:

Over 60% = another ethnicity or race other than White

25% = foreign-born

If 1 in every 54 children is diagnosed with autism according to the CDC, then there are at least 1100 families with children with ASD on Staten Island.

Problem: Caretaker Burnout

Caretaker burnout: A state of physical, mental, and/or emotional exhaustion that may be accompanied by a change of attitude

- Can lead to stress, fatigue, alterations of sleeping patterns, lowered immunity
- Can also result in inadequate care and unintentional mistreatment for people with ASD

A study of maternal caregiving burden in Turkish children with ASD showed that higher caregiver burden was associated with lower life satisfaction (7). Lower life satisfaction \rightarrow depression, anxiety, decreased quality of care for their children, and possibly negative physiological effects.

Caregivers of children with ASD compared to caregivers of children with other disabilities: More psychological distress associated

- Depression
- Anxiety
- Decreased family cohesion
- Caregiver burnout (2)

"Parental stress is an important predictor for intervention outcomes in children with ASD like lower levels of developmental improvement in behavioural interventions, including decreased development of language, communication and other adaptive behaviours" (8)

Caretakers need to remember that in order to take care of the child with ASD, they need to make sure that they are healthy. "If you don't take care of yourself, you won't be able to care for anyone else" (9).

Autism Speaks organization found that mothers of children with autism benefit significantly from weekly stress-reduction classes led by other mothers. The classes:

- Reduced high levels of personal stress, anxiety and depression
- Improved the mom's interactions with their children (10).

Proposed Solution: The SAM Project

How Yoga can be used as a way of combatting caretaker burnout:

- Yoga targets unmanaged stress
- Reduces activity of the sympathetic nervous system and decreases levels of cortisol (stress hormone)
- This increases resilience and improves mind-body awareness (11).
- Yoga can help caregivers develop higher resilience
- In a study that analyzed the health of caregivers of people with autism:
- High resilience → lower cortisol levels → better perceived health
- With the right amount and type of support, caregivers can develop higher resilience to combat caregiver burnout and stress (12)

The purpose of the SAM Project is to help participants (both caregiver and children with ASD) get in touch with their inner calm and combat their anxiety.

The program aims to:

- Help both caregivers and children with ASD manage
- Provide the option to caregivers of either participating with their children, or simply leave their children with instructors to allow for time to engage in self-care behaviors
- Support caregivers to allow for development of resilience

The class features:

- Calming music: centers the mind and body and slows down the sensory system's over-processing of
- Yoga poses: enhance flexibility, muscle tone and body awareness
- Individual goal-setting: become more comfortable stretching both their body and their mind
- Create an atmosphere where participants can make social connections and share meaningful communication
- Trust-building exercises
- Focus on strengthening the mind and body with teamwork and self-reliance

Learning Objectives:

Caretakers of the ASD Population should be able to:

- 1) Seek social support groups and programs;
- 2) Participate in yoga to alleviate and prevent caregiver stress and burnout;
- 3) Exhibit other self-care behaviors such as exercising, socializing, engaging in hobbies.



References

(1) McIntosh E. As autism rate rises, funding to Staten Island agencies gets slashed-Staten Island Advance. 2017; Available from https://eden2.org/blog/as-autism-rate-rises-funding-tostaten-island-agencies-gets-slashed-staten-island-advance/

(2) Nik Adib N, Ibrahim M, Ab Rahman A, Bakar R, Yahaya N, Hussin S, Wan Mansor W. Perceived Stress among Caregivers of Children with Autism Spectrum Disorder: A State-Wide Study. 2019: Available from

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6517964/

(3) Betts DE, Betts SW. Yoga for Children with Autism Spectrum Disorders: A Step-by-Step Guide for Parents and Caregivers. Jessica Kingsley Publishers; 2006.

(4) Garcia JM, Baker K, Diaz MR, Tucker JE, Kelchner VP, Rice DJ. Implementation fidelity of a mindfulness-based yoga program for children with autism spectrum disorder and their families: A pilot study. Advances in Neurodevelopmental *Disorders.* 2019;3(1): 54–62. Available from: https://ezproxy.wagner.edu:2310/10.1007/s41252-018-0091-3

(5) Census A. Census profile: Staten Island borough, Richmond County, NY. 2019; Available from

https://censusreporter.org/profiles/06000US3608570915staten-island-borough-richmond-county-ny/

(6) N & N. Staten Island Community Board #1. In Staten Island Community Board 1. Staten Island, NY: Community District Profiles. 2017: Available from:

https://communityprofiles.planning.nyc.gov/staten-island/1

(7) Cetinbakis G, Bastug G, Ozel-Kizil E.T. Factors contributing to higher caregiving burden in Turkish mothers of children with autism spectrum disorders. International Journal of Developmental Disabilities. 2020;66(1): 46-53. Available from https://www.tandfonline.com/doi/abs/10.1080/20473869.2018.14

(8) Begum R, Mamin F. Impact of Autism Spectrum Disorder on Family. 2019; Available from:

https://www.longdom.org/open-access/impact-of-autismspectrum-disorder-on-family-44919.Html

(9) Maur J. Same Great Leadership, Same Great Mission. Bridgeway Academy. 2019; Available from: bridgewayohio.org/uncategorized/caregiver-burnout/

(10) Caring for the Caregiver. Available from https://www.autismspeaks.org/tool-kit-excerpt/caring-caregiver

(11) Novotney A. Yoga as a practice tool. Monitor on Psychology. 2009;40(10). Available from: http://www.apa.org/monitor/2009/11/yoga

(12) Ruiz-Robledillo N, De Andrés-García S, Pérez-Blasco J, González-Bono E, Moya-Albiol L. Highly resilient coping entails better perceived health, high social support and low morning cortisol levels in parents of children with autism spectrum disorder. Research in Developmental Disabilities. 2014;35(3): 686-695.