



# Stress Reduction Through a Group Respite Intervention for Parents of Children with Special Needs

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# Disclosure

There are no conflicts of interest for this presentation

This project is partially funded by continued support from the Rhode Island Lifespan Respite Grant, through the Office of Healthy Aging.

# Objectives

Describe the use and effectiveness of a mixed method approach to program evaluation.

Demonstrate an understanding of the stress related to long-term family caregiving for children living with special needs.

Engage with other family support professionals to address the needs of family caregivers.

# Background

- The grant is funded through the Department of Health and Human Services, Office of Healthy Aging.
- Community partners include Catholic Social Services, the United Way, and Healthcentric Advisors.
- Nursing faculty from five nursing programs from different academic institutions in Rhode Island coordinate student involvement.
- Short video: <https://youtu.be/cJfC1laKMxU>

# How it all began....

- ★ Started in 2014/2015....many table-top discussions.
- ★ Spring 2016: Began the provision of in-home respite for a handful of families – two academic partners: URI and RIC.
- ★ Each of the following semesters has brought more families and increased student nurse participation with additional nursing programs.
- ★ Fall 2018: Monthly Group Respite for children with special needs.
- ★ Fall 2019: DPT program interest and use of Independence Square for group respite site.
- ★ Spring 2021: Increased Group Respite to 2 x monthly
- ★ Spring 2023: Dissertation study – weekly Group Respite

# Family caregivers

- Estimated 1.5 billion hours of care at home, in the United States, is provided by family caregivers of children living with special needs. This calculates to an annual cost of care estimate between \$12-36 billion depending on the skill level required to provide care (Romley et al., 2017).
- In 2015, 18% of family caregivers were providing care at home.
- In 2020, 21 % of family caregivers were providing care at home.
- 5.7% of that 21% were providing care for children living with special needs.

Romley, J., Shah, A., Chung, P., Elliott, M., Vestal, K., & Schuster, M. (2017). Family-provided health care for children with special health care needs. *Pediatrics*, *139*(1): e20161287. <https://doi.org/10.1542/peds.2016-1287>

American Association of Retired Persons (AARP) and National Alliance for Caregiving (NAC). (2020). Caregiving in the United States 2020. <https://doi.org/10.26419/ppi.00103.003>

# Healthy People 2030

Healthy People 2030 has a focus on improving the health and well-being of parents and caregivers and those they care for within their community.

Health conditions

Healthy behaviors

Populations

Settings

Social determinants of health

# Impact of caregiving

- Some parents do not express need for help until they reach the point of physical and emotional exhaustion after years of care (Dubois et al., 2023).
- Become overwhelmed with their conflicting roles of parent, caregiver, and therapy provider, having to adjust their future expectations for themselves and their child (Beckers et al., 2021).
- Aging population increases likelihood of parents caring for a child will also care for an older adult family member.
- About 15% of global population (over 1 billion people) live with some form of disability/special needs (WHO, 2020).

Dubois, A. C., Seghers, N., Van Dorsselaer, I., Dario, Y., Swolfs, I., & Gerain, P. (2023). “Already too late”: A qualitative study of respite care among mothers of children with special healthcare needs and disabilities. *Journal of Pediatric Nursing*, 72, e114-e121. <https://doi.org/10.1016/j.pedn.2023.06.017>

Beckers, L. W. M. E., Smeets, R. J. E. M., & Van der Burg, J. W. (2021). Therapy-related stress in parents of children with a physical disability: A Specific concept within the construct of parental stress. *Disability and Rehabilitation*, 43(8), 1185-1192. <https://doi.org/10.1080/09638288.2019.1646815>

World Health Organization (2020). [www.who.int/news-room/fact-sheets/detail/disability-and-health](http://www.who.int/news-room/fact-sheets/detail/disability-and-health)



# Covid-19 Impact

The pandemic magnified the intensity of family caregiver stress as families experienced substantial disruption to their normal routine, including children at home instead of school and the absence of in-home services.

85% of family caregivers of children and adults reported mental health symptoms -late 2020; early 2021.

Czeisler, M., Rohan, E., Melillo, S., Matjasko, J., DePadilla, L., Patel, C., Weaver, M., Drane, A., Winnay, S., Caodilupo, E., Robbins, R., Wiley, J., Facer-Childs, E., Barger, L., Czeisler, C., Howard, M., & Rajaratnam, S. (2021). Mental health among parents of children aged <18 years and unpaid caregivers of adults during the covid-19 pandemic – United States, December 2020 and February-March 2021. *Morbidity and Mortality Weekly Report*, 70(24), 879-887.

What we know: sometimes, it's the caregivers that need to be taken care of.

- In Rhode Island, we have found an innovative way to utilize nursing and PT students as volunteers to help supplement the respite workforce.
- Students are awarded clinical hours for participation in the respite program.

# Aim of dissertation study

- To gain an increased understanding of the effectiveness of a group respite intervention by assessing change in the self-reported stress level of parents/guardians of children living with special needs and their overall experiences and perceptions related to group respite.

A mixed-methods research design was used. Spring 2023.

# The Group Respite Intervention

- Weekly – every Saturday x 12 weeks during the spring 2023 semester.
- Four-hour group respite each Saturday, 12-4pm.
- Respite workers = nursing and physical therapy students; supervised by faculty.
- Ratio of 1:1, student:child.
- The respite intervention included companionship, direct care (i.e. feeding, medication administration, diaper changes, positioning) therapeutic and general play, walks, and conversation (verbal, non-verbal, communicative devices).

# Demographic Data: parents

Convenience sample

English speaking parents

Child (< 18yrs) enrolled in group respite

100% completion of pre, post, and interview

Age range 33-58yrs mean 42.6yrs

All identified as white

Total participants N = 16	N	%
<b>Gender:</b>		
Female	12	75%
Male	4	25%
<b>Relationship status:</b>		
Married	9	56%
Single	7	44%
<b>Education:</b>		
< high school	1	6%
High school	3	19%
Secondary/vocational	12	75%
<b>Annual family income:</b>		
<50,000	2	12.50%
50-75,000	2	12.50%
75-100,000	4	25%
100-125,000	3	19%
125-150,000	0	0%
>150,000	5	31%
<b>Use of other services:</b>	10	62.50%

# Demographic Data: children

3 with G-tube feedings

2 required assistance with oral feeding

3 non-ambulatory

8 non-verbal

Age range 3-15yrs

Mean 9.6yrs

Gender:	N	%
Female	10	62.50%
Male	6	37.50%
Race		
white	13	81.00%
mixed	3	19.00%
Program Attendance:		
1	1	6%
2 to 3	4	25%
5 to 6	4	25%
8 to 9	2	12.50%
> 10	4	25%
Primary diagnosis/special needs:		
Cognitive/motor delay	6	37.50%
Hearing loss	1	6%
Down syndrome	4	25%
Cerebral Palsy	3	19%
Epilepsy	2	12.50%
Autism	8	50%
ADHD	4	25%
Congenital cardiac defect	2	12.50%
Chronic lung disease	1	6%
Prader-Willi Syndrome	1	6%

# Kingston Caregiver Stress Scale (KCSS)

Providence  
Care

**Kingston Caregiver Stress Scale (KCSS)**

Patient Name: \_\_\_\_\_ Case #: \_\_\_\_\_

Caregiver: \_\_\_\_\_ Relation to Patient: \_\_\_\_\_ Date: \_\_\_\_\_

Lives in: Community  Long Term Care Facility  Other



Some people report feelings of stress surrounding certain aspects of care giving. To what extent, if any, do these apply to you in your role of care giving to your spouse or relative? Using a 5 point rating scale, where 1 equals no stress and 5 equals extreme stress, indicate the extent of the stress or frustration you feel surrounding the following issues.

	1	2	3	4	5
	<i>Feeling NO Stress (Coping fine, no problems)</i>	<i>Some Stress</i>	<i>Moderate Stress</i>	<i>A lot of Stress</i>	<i>Extreme Stress (Feeling at "end of rope", health at risk)</i>
<b>CARE GIVING ISSUES</b>					
TO WHAT EXTENT...					
1	Are you having feelings of being overwhelmed, over worked, and/or over burdened?				
2	Has there been a change in your relationship with your spouse/relative?				
3	Have you noticed any changes in your social life?				
4	Are you having any conflicts with your previous daily commitments (work/volunteering)?				
5	Do you have feelings of being confined or trapped by the responsibilities or demands of care giving?				
6	Do you ever have feelings related to a lack of confidence in your ability to provide care?				
7	Do you have concerns regarding the future care needs of your spouse/relative?				
<b>FAMILY ISSUES</b>					
TO WHAT EXTENT...					
8	Are you having any conflicts within your family over care decisions?				
9	Are you having any conflicts within your family over the amount of support you are receiving in providing care?				
<b>FINANCIAL ISSUES</b>					
TO WHAT EXTENT...					
10	Are you having any financial difficulties associated with care giving?				

This form should be used in conjunction with the **KCSS Administration and Interpretation Manual** which can be freely downloaded from: [www.kingsstoncare.ca](http://www.kingsstoncare.ca) or email: [kscalee@queeneu.ca](mailto:kscalee@queeneu.ca)

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# Findings from pre & post stress scale

- **Bold** = statistical significance < 0.05; highly significant < 0.01

Question 1	3.78	0.88	3.06	1.06	0.72	0.63	0.16	0.38	1.06	4.55	<b>&lt;0.001</b>
Question 2	3.09	1.27	1.50	0.73	1.59	1.25	0.31	0.93	2.26	5.08	<b>&lt;0.001</b>
Question 3	3.59	1.28	1.81	0.98	1.78	1.33	0.33	1.07	2.49	5.36	<b>&lt;0.001</b>
Question 4	3.34	1.38	2.19	1.17	1.16	1.75	0.44	0.22	2.09	2.65	<b>0.018</b>
Question 5	3.31	1.40	2.44	1.36	0.88	0.81	0.20	0.45	1.31	4.34	<b>&lt;0.001</b>
Question 6	2.88	1.26	2.06	1.12	0.81	1.17	0.29	0.19	1.43	2.78	<b>0.014</b>
Question 7	3.81	1.33	3.25	1.69	0.56	1.37	0.34	-0.17	1.29	1.65	0.120
Question 8	2.25	1.18	1.69	1.01	0.56	1.21	0.30	-0.08	1.21	1.86	0.083
Question 9	2.72	1.39	1.94	1.12	0.78	1.62	0.41	-0.08	1.65	1.93	0.073
Question 10	2.44	1.31	1.94	1.12	0.50	1.21	0.30	-0.15	1.15	1.65	0.119
Total	31.22	10.02	21.69	8.05	9.53	8.46	2.11	5.03	14.04	4.51	<b>&lt;0.001</b>
SD=standard deviation											
SE=standard error of mean difference											



# Pre and post KCSS total score by participant

Pre: score range 11-44, mean 31.22

Post: score range 10-36, mean 21.69

Mean reduction in overall stress by 9.53 points from the pre to the post-intervention stress survey (95% confidence, p-value of <0.001).

Participant	Total-pre	Total-post
1	34	33
2	22	25
3	28	22
4	25	18
5	4	25
6	39	31
7	30	12
8	29	24
9	40.5	14
10	44	28
11	37	24
12	30	19
13	11	10
14	12	10
15	36	16
16	38	36

Possible score range:  
10-50 points

<16 = low stress

16-24 = moderate stress

>24 = severe stress

81% = severe on pre

38% = severe on post

# Post program interview

1. In what ways has group respite most benefited you?
2. Please describe some of the activities you were able to do during the respite time that otherwise you are not able to do.
3. In what ways has group respite been challenging?
4. What are your recommendations for respite?

Qualitative data from post group respite intervention interviews were audio recorded, transcribed, and analyzed; identifying common categories among the interview responses.

Interrater reliability was conducted through dual review of interview transcripts.

# Major common categories identified by parents in post intervention interview

Safe place for their child to go without parental presence [81%; n=13]

Trust in the care and supervision provided by respite workers [56%; n=9]

Time to spend on activities not focused on their child. [100%; n=16]

\*63% of the parents noted all 3 categories as benefits of the group respite.

# Sub-categories based on activities parents engaged in during group respite time:

self-care [75%; n=12]

accomplishing needed or wanted tasks [56%; n=9]

focus on others [69%; n=11]

# Challenges

Driving distance and time...wanting morning hours.

63% (n= 10) indicated there were no challenges, only benefits

- *I can't think of any challenges. He came home with a big smile on his face. From what I understand, he was giving the respite worker kisses! He was very happy. I can't think of any down sides.*
- *Only when it ends! Because my kids love it!*
- *It has only helped; my special needs child looks at group respite as a reward because he gets so much attention from everybody.*

# Recommendations made by parents

All 16 parents (100%) expressed the need for **more** respite care opportunities.

overnight respite as a major need.

Need for other locations.

Respite help that incorporates parents... such as a beach day, where they need extra help to supervise.

# Summary of study

- The 12-week group respite intervention was found to produce measurable stress reduction among the parents in this study using the KCSS.
- The stress relief was also reflected in the parents in this study's tone of voice as they talked of respite as a moment to breathe, listen to their own thoughts, let their guard down and simply relax.
- The qualitative portion allowed the parents to reflect upon the experience and provide future recommendations on respite...providing us with future implications.

# Limitations

As a small size, convenience sample of parent caregivers, where there was a lack of racial/ethnic diversity among participants, the results are not generalizable.

Parents registered their child based on word of mouth and parent support networking...illustrating their connectedness and resourcefulness for locating programs beneficial to them and their children. Thus, did not reach those from underserved community/not internet connected.

The cons to this approach, as opposed to a randomized controlled trial with a large sample size, is the inability to compare study participants' stress scores who receive an intervention vs those who do not.



# Implications for Research

Longitudinal studies to assess parental stress over time.

Larger sample size studies.

Comparing the stress level of parents who have respite services vs those who do not.

Comparison studies on a variety of respite interventions.

Studies on the provision of other services in conjunction with the group respite and their effect on family caregiver stress.

# Implications for Practice

Routine stress screening using the KCSS, and guiding family caregivers toward resources and improve access to programs to alleviate their stress.

Client advocacy and anticipatory guidance at the primary care level can provide focus from a proactive standpoint that is person/family centered.

Nurses need to meet the family caregiver where they are most likely to engage.

Healthcare providers must be made aware of programs and resources for families that are paid and unpaid.

# Implications for Education

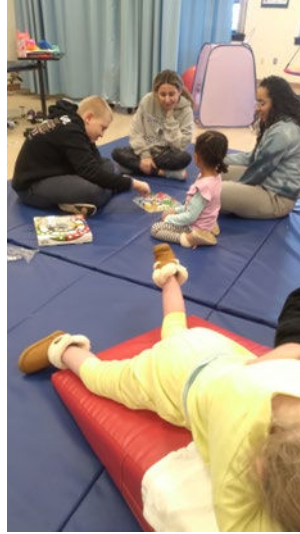
As outlined in the American Association of Colleges of Nursing's *The Essentials: Core Competencies for Professional Education* (2021), the provision of individualized care and attention, which is the focus of respite care, aligns with the domain of person-centered care; addressing the needs of a target population while considering the socioeconomic impact of available care aligns with the domain of population health; and working collaboratively with other disciplines aligns with the domain of interprofessional partnerships.

Expand experiential learning: The group respite intervention can offer students from many disciplines an opportunity to collaborate through a team approach in an interprofessional education experience.

American Association of Colleges of Nursing. (2021). *The Essentials: Core competencies for professional nursing education*.

# The joy of this work:





# Roles and Responsibilities of Students

Safety & companionship with the children; opportunity for family caregiver to do something for themselves.

## **Activities students engage in during respite**

- Walks
- Playing cards/games/puzzles/bubbles/...
- Assisting with ADLs, such as hand washing, feeding, diaper changes...
- Therapeutic play
- Companionship
- Conversation
- Communicate and update family caregiver of time spent during respite visit.

# Where We are Now and Where We Want to Go...

- Expanded to all the current nursing programs in the state of Rhode Island
- Reach the underserved communities and offer respite services to those who may not know how to access resources and services.
- Obtain dedicated building space for a Respite and Experiential Learning Center in RI

# Discussion and questions



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