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The Efficacy of the Healthy Families Flourish Program for Families Raising Children with Autism Spectrum Disorder

Carli Madalena Rita

University of New Hampshire, Durham

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**The Efficacy of the *Healthy Families Flourish Program* for Families Raising Children with
Autism Spectrum Disorder**

Carli Madalena Rita

Department of Occupational Therapy, University of New Hampshire

OT 791 (01): Senior Honors Thesis

Dr. Sarah L. Smith

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Abstract

The family unit is the driving force that creates a foundation for life satisfaction and wellbeing of a child that extends across the lifespan. Understanding family health and family participation in meaningful daily activities are critical components of family life lacking in current research, especially for families raising children with autism spectrum disorder (ASD). This study seeks to determine the effectiveness of an occupational therapy intervention program designed to support families raising children with ASD to identify and overcome barriers to everyday family activities. The *Healthy Families Flourish Program* is a 10-session occupational therapy intervention program developed for this study which uses a coaching-based approach to support families. Recruitment of four participant is established using convenience sampling methods via social media platforms. The program is delivered via telehealth and consists of a six-phase coaching process in which family identified goals, strategies, and evaluation drives the occupational therapy process. Quantitative assessment methods before and after the intervention program determine if the program is effective in increasing family health and engagement in everyday family activities. Preliminary results indicate that the intervention program is effective in improving cohesion, engagement levels, and family communication among participant families. Expanding the current studies' findings with further research may provide evidence to support occupational therapy practice via telehealth for families raising children with autism spectrum disorder desiring to improve family health and occupational participation.

Families are potentially the most critical units of being for the human person (Newland et al., 2015). Family health is reflective on the overall life satisfaction, development, and wellbeing of all individuals involved (Newland et al., 2015), however, achieving and maintaining consistency may be difficult for some families, particularly those raising children with ASD (Stein et al., 2011). Autism spectrum disorder refers to a developmental disability that may cause significant social, communication, and behavioral challenges (American Psychiatric Association [APA], 2013). Due to the varying degree of symptoms that may present, each individual with the diagnosis presents unique challenges (Baio et al., 2018). Certain individuals with ASD are entirely independent while others require significant support in all aspects of life (Baio et al., 2018).

Family and individual participation in desired occupations, or meaningful activities that individuals need or desire to do, are often unfavorably affected by an ASD diagnosis (Stein et al., 2011), causing a potential imbalance in family function and prioritization of the child's needs over family needs (Breitkreuz et al., 2014). Typical deficits in the areas of feeding, toileting, self-care, communication, and social interaction are common for children with autism spectrum disorder (Kuhaneck et al., 2015). These challenges, along with a child's unpredictable behaviors, physical aggression, self-injury, and social isolation has potential to disrupt balance within a household unit (DeGrace et al., 2014). Early intervention services provide opportunity to work towards positive familial health change; however, once the child begins school-based services, family needs are often overlooked in order to prioritize the child's personal and educational needs.

Similarly, research concentrated on children with ASD typically focus on personal and functional challenges that individuals with the disorder face (APA, 2013). Less research

examines family health within households raising children with ASD despite the disorder's implications on the health and participation of the family unit. Understanding the challenges faced by the entire household is critical in providing necessary support as raising a child with ASD may have a considerable impact on family functioning and satisfaction (Kahuneck et al., 2015). Financial hardships, frequent medical appointments, and concerns for the future make raising a child with ASD stressful and difficult (Kahuneck et al., 2015). Particularly for families with limited financial resources, lack of support, or restricted geographic access, there arises an increased difficulty to create family opportunities and provide necessary family attention (DeGrace et al., 2014). Often, this results in poorer family health for families raising children with disabilities when compared to families with typically developing children (Breitkreuz et al., 2014).

Lasting behaviors associated with ASD coupled with numerous intervention options create an emotional strain on the everyday lives of families raising a child with the disorder (DeGrace et al., 2014). These families cope with atypical barriers that are not present in the lives of families raising typically developing children as they attempt to establish regularity in their own home (Breitkreuz et al., 2014). For this reason, interventions to decrease stress and improve parental competence, self-confidence, and coping skills are a necessary aspect of family-centered care for families raising children with ASD (Kahuneck et al., 2015).

Early intervention services, provided for families of children ages birth through five, has potential to positively influence family health outcomes (APA, 2013). Following these services, the telehealth coaching model can provide continued support for families raising school-aged children with ASD, especially for those who would have difficulty accessing typical support resources. Telehealth is an advanced service-delivery approach in which medical and health

services are provided via communication and information technology, granting feasible, cost-effective access for all (American Occupational Therapy Association [AOTA], 2018). The telehealth delivery approach is a way to enhance care by aligning with the routines that establish regularity in the home (Little et al., 2018).

The purpose of this study is to determine the effectiveness of the *Healthy Families Flourish Program* (HFFP) on improving overall family health and family participation in everyday activities for families raising school-aged children with autism spectrum disorder. The research question is as follows: What is the preliminary effectiveness of the HFFP in improving family health and occupational participation for families raising school-aged children with autism spectrum disorder?

Methods

Design

This project is part of a larger family health study within the University of New Hampshire Healthy Families Research Program. This project utilizes a single subject experimental design to examine the effectiveness of the HFFP by using pre- and post-intervention measures across all participants. This study was reviewed and approved by the UNH Institutional Review Board to ensure the protection of study participants. All participants consented to study participation in the initial family meeting. Consent meetings were held prior to the start of the program. Adult consent and parental consent were signed for and child assent for personal participation was verbally provided.

Procedures

Four families were recruited for study participation via recruitment postings on social media networks, the UNH Healthy Families Research Program, and email to professional contacts. For study eligibility, families must: a) have at least one child ages 2-17 with a diagnosis of ASD who is living in the home full time as confirmed by a signed parental statement of such, and b) speak English. Exclusion criteria includes: a) the child is not living in the home, and b) autism spectrum disorder is not the primary diagnosis of the child.

Intervention

The *Healthy Families Flourish Program* is a 10-session occupational therapy intervention based upon the Family Health Model (Smith et al., 2017). The HFFP was delivered via telehealth using Zoom, a web-based conferencing platform at the UNH Telehealth Practice Center. Families accessed the sessions from their smartphone, tablet, or computer at a location of their convenience, typically their home. Across sessions, families participated in a 6-phase coaching process to include: 1) initial evaluation and information gathering, 2) goal setting, 3) action planning, 4) enacting the plan, 5) evaluating performance, and 6) generalizing skills.

Dr. Sarah L. Smith, a licensed occupational therapist, oversaw the intervention and supervised implementing intervention strategies for families. Researchers worked together with the family to create goals, interventions, and evaluation methods that support the family's everyday life. Data was collected from families before and after the intervention program.

Measures

To examine the preliminary effectiveness of the HFFP, data was collected via one consolidated UNH Qualtrics survey that integrated the tools listed below. The survey was completed by all individual family member participants within two weeks before and after the intervention program. Both mean and median pre- and post-intervention scores were compared

using a nonparametric t-test to analyze significant of the change scores to determine if the intervention created any change.

The following measures were used to determine if the intervention created a change in family health:

Satisfaction with Family Life Scale (SWFL), (Zabriskie & Ward, 2013). The SWFL is a self-reported five-item Likert-type scale measuring family members' satisfaction with family life. The SWFL has comprehensive evidence of internal consistency (Chronbach's alpha 0.91-0.94), test-retest reliability ($r=0.87$), and criterion and construct validity (Zabriskie & Ward, 2013).

Family Adaptability and Cohesion Evaluation Scale (FACES) IV, (Olson et al., 2006). The FACES-IV is a 62-item Likert-type self-report assessment measuring family functioning in the areas of cohesion, flexibility, and communication. The FACES IV Package combines the FACES IV 42 items with the Family Communication Scale (10 items) and the Family Satisfaction Scale (10 items). The FACES IV demonstrates evidence of strong reliability and validity (Olson, 2011).

To determine if the program created any change in occupational participation in participant families, the following measure was used.

Goal Attainment Scaling (GAS), (Kiresuk et al., 1994). Goal attainment scaling is an evidence-based outcome measurement tool affording measurement of highly individualized and contextualized change on client's goals (Harpster et al., 2019; Kiresuk et al., 1994). At the beginning of the intervention, at least two GAS goals were collaboratively developed with each family specifically related to family involvement in daily activities. Progress on these goals was measured upon completion of the intervention.

Data Analyses

Wilcoxon nonparametric t-tests were used to examine the change in family health and occupational participation among participant families. Descriptive statistics were used to analyze the GAS taking the average scores of the family's top two goals both pre- and post-intervention. Mean scores were used from all measures in analyses. All families had one participant complete all measures, and two families had two participants complete all measures.

Results

Participants

Four participant families were recruited for this study and completed the entirety of the program. Each family had at least one child with an ASD diagnosis. All participants families are living within the state of New Hampshire. Six caregivers completed both pre- and post-intervention surveys and participant characteristics are presented in Table 1. Of the four participant families, six primary caregivers participated in the intervention sessions. This included three mothers, two fathers, and one grandmother. Ten total children were involved based on parental and child consent. Of those children, three children were active participants in intervention sessions while seven were not active due to family preference.

Family Health

To measure family health, the FACES IV measure was used. This measure categorizes family health into the areas of balanced cohesion, balanced flexibility, enmeshed, disengaged, rigid, and chaotic. Results show that the intervention program was successful in significantly improving levels of balanced cohesion and engagement among families ($p < 0.05$). Although not statistically significant, the intervention program showed slight improvement for families in the

areas of balanced flexibility, enmeshment, and chaos levels. Rigidity was the only family health area of the FACES IV that did not improve, but rather worsened over the course of the program.

Family Communication

Family communication is defined as the act of making information, ideas, thoughts and feelings known among members of a family unit (Olsen et al., 2006). Results from the FACES IV indicated statistically significant improvements in family communication following the intervention program ($p < 0.05$). This area of family health demonstrated the greatest change pre- and post-intervention.

Family Satisfaction

To measure family satisfaction, both the FACES IV and SWFL was employed. Neither measure showed statistically significant results, however, slight improvement was noted on both measures (See Table 3). The tools may have not been sensitive enough to capture the smaller changes happening within participant family lives.

Occupational Participation

Prior to the intervention program, each family identified two to three goal areas that they would like to focus on throughout the program. Each family's top two goals were used for data analysis purposes, resulting in a total of eight goals across participant families. Based on the GAS, all families showed progress toward at least one goal by the end of the program (see Table 4). Many family goal areas identified were similar between families, and includes areas of family participation, house tidiness, sibling relationships, and meal preparation.

Discussion

Discussion of Findings in Light of Previous Literature

Results of this study indicate that a 10-week occupational therapy based coaching program delivered via telehealth is effective in supporting improvement upon family health and family communication for families raising school-aged children with ASD. This is the first preliminary study to emphasize improving outcomes at a family level for this population. Previous studies examining family health found that the construct is a dynamic journey that may follow many different paths (Smith et al., 2021). For families with a recently diagnosed child, normalcy in everyday life may look different as they navigate the unknown of what is to come (DeGrace et al., 2014).

Previously studied occupation-based coaching methods similarly found that this model may improve parent-identified goals as it gives families the opportunity to develop their own objectives and approaches to improving daily life (Little et al., 2018). Further, occupation-based coaching provides families with skilled professional to support daily life and offer input about implementation strategies in the home. This coaching method, which has been previously examined in conjunction with the telehealth service delivery model, has been shown to support delivery and administration of services to families who may not have access to traditional services (Little et al., 2018). The telehealth platform additionally aligns well with the client-centered quality of the occupational therapy profession as a whole as it gives the opportunity for therapists to see families in their most natural context.

While the sample size of this study does not meet the criteria for normalcy, the preliminary findings suggest that occupational therapy has the ability to positively impact family life for families raising children with ASD specific to family health and family communication. Family health was shown to improve in many areas measures by FACES IV. While the FACES IV tool does not measure family health in its nature, it measures several constructs relating to

family health as defined by this study. Rigidity, the only family health area to decline throughout the program, is a common characteristic of ASD. As families worked toward organizing daily life and creating structure through routines, it is not surprising that a decline in rigidity resulted. All other areas, including cohesion, flexibility, engagement, enmeshment, and chaos levels improved as families worked together to make progress on their goals.

Communication is a critical aspect of family life that improved throughout the intervention program. Communication is generally accepted as one of the most critical aspects of interpersonal relationships which is related to family interactions throughout the program (Olson et al., 2006). As participants began to communicate openly about their family life, they became more comfortable in doing so. Initial conversations about personal life were challenging for some participants, however, participants ultimately were able to be open in conversation and identify areas of family life that needed improvement as well as strategies on how to progress toward their goals. While they made progress on communication with researchers, they also did so with each other, leading to significant conversations on how to sustain change in everyday life.

In beginning to recognize areas of need in family life, participants became more aware of their family circumstances. For this reason, it was not surprising that family satisfaction did not greatly improve following the intervention program. Although it improved slightly, family satisfaction levels were still noted to be low post-intervention. Perhaps families realized their own dissatisfaction in speaking about what areas of family life could be improved. The two tools measuring family satisfaction levels may not have been sensitive enough to capture the smaller changes occurring within participant families regarding satisfaction with family life.

One of the primary findings of the study was the increase in occupational participation post-intervention as measured by the GAS. This intervention program is the first of its kind to look at family-based outcomes utilizing occupational therapy intervention. Previous research suggests that children with ASD have difficulty with activity participation (Little et al., 2018). However, these findings align with current research indicating that parent-identified goals and strategies better prepare families for challenges that may arise during activity participation (Little et al., 2018).

Real World Impact of Findings

The results of this study have several implications for occupational therapy practice. Families raising children with ASD may be challenged in their everyday lives, resulting in modification of routines in order to accommodate the needs of the child with ASD (DeGrace et al., 2014). Oftentimes, this has subsequent effects on family health and the scope of activities in which the family chooses to engage in (DeGrace et al., 2014). This study aimed to address family outcomes through intervention related to children with ASD. The examination of preliminary effectiveness will improve presently lacking scientific research knowledge and provide significant information regarding family health to the field of occupational therapy.

The telehealth delivery model utilized in this program was successful in providing families with the necessary support and resources required to improve family health and occupational participation outcomes. Prior to COVID-19, telehealth was an underutilized service that is now being used in combination with traditional service delivery. Participant testimonials support telehealth for this population and it grants opportunities to align with daily routines while taking place in a comfortable and convenient space. Occupational therapists may consider continuation of services via telehealth following COVID-19 mandates increased access for all.

Finally, occupation-based coaching methods were shown to support improvement in areas of family health and family communication. These family-driven models may be used in the future to support family health improvement and success in goal attainment. Augmentation to traditional child-focused services that include family goals and objectives may create more balanced homes and increase family health and occupational participation among families raising children with ASD.

Limitations and Future Research

Discussing family health and taking active steps to address potentially poor family health may have created discomfort and feelings of unease for participants. COVID-19 impacted this study in ways that were not applicable to family life when this study was designed. It quickly became evident that all participant families were impacted COVID-19 in some way. Many families struggled with maintaining routines, remote learning, self-care, balance, and designating time with family members when the majority of time was spent together in the home. The purpose of this study was not to focus on family life during a pandemic, but because it was a substantial reality, the impact of COVID-19 on participants' lives became a common topic. However, this study came at an important time as many child-focused services were paused during this time. During the time this intervention was administered, families were in need of services both for their children and family units, giving researchers the opportunity to make significant impacts on participant family lives.

The small sample size created limitations for this study, however, due to the novel nature of this program, a small sample size and lack of control group was necessary to see if the program was feasible and effective for families. Self-report measures were used during this study. Using self-report measures limited this study in several ways as participants may not be

able to assess themselves accurately. Employing observational measures and rating health on professional observation may benefit future research. Additionally, utilizing researchers that are blind GAS goal graders would eliminate any biases or grading of goals based on what the grader knows about the family.

Future research will continue to analyze family-based outcomes for families raising school-aged children with ASD and take limitations of this study into account. Additional research with larger sample sizes, a control group, and observational measures would augment the results of this study for occupation-based coaching potentially increasing family health and occupational participation for families.

Conclusion

This study sought to examine the preliminary effectiveness of the *Healthy Families Flourish Program* on improving overall family health and family participation in everyday activities for families raising school-aged children with autism spectrum disorder. The findings show that the program was successful in improving some areas of family health and family communication. More specifically, results show significant improvements in the family health areas of cohesion and engagement. Further research that continues to examine occupation-based coaching methods for improving family outcomes is required to draw further conclusions and determine best practice. This preliminary study shows promise that family-based outcomes may become routine to improve not only child participation but family participation as well.

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Table 1*Demographics*

Characteristic	n = 6 (%)
Gender	
Female	4 (66.7%)
Male	2 (33.3%)
Age	
35-44	2 (33.3%)
45-54	4 (66.7%)
Ethnicity	
Non-Hispanic or Latino	6 (100%)
Race	
Asian or Asian American	2 (33.3%)
Non-Hispanic White	3 (50%)
Other	1 (16.7%)
Employment status	
Employed full time	5 (83.3%)
Unemployed for more than 1 year	1 (16.7%)
Education	
Some college or technical school	1 (16.7%)
Associate degree	1 (16.7%)
Bachelor's degree	1 (16.7%)
Master's degree	3 (50%)
Family structure	
Two parent household (biological/adoptive)	3 (50%)
Two parent household with at least one stepparent	2 (33.3%)
Other	1 (16.7%)
Household income	
\$50,000-\$74,999	1 (16.7%)
\$75,000-\$99,999	1 (16.7%)
\$100,000-\$149,999	3 (50%)
\$200,000 and over	1 (16.7%)

Table 2*Family Adaptability and Cohesion Evaluation Scale (FACES) IV Results (N =6)*

Family Health Area	Pre-Intervention	Post-Intervention	<i>p</i>
Balanced cohesion			0.028
M	53.33	63.33	
SD	11.22	11.26	
Balanced flexibility			0.068
M	51.0	61.33	
SD	14.78	12.19	
Disengaged			0.028
M	42.50	25.33	
SD	21.13	8.73	
Enmeshed			0.144
M	24.67	21.33	
SD	7.23	6.41	
Chaotic			0.180
M	28.0	22.67	
SD	12.90	13.49	
Rigid			0.115
M	38.50	47.0	
SD	78.62	8.81	
Family communication			0.028
M	34.0	58.50	
SD	23.53	21.40	
Family satisfaction			0.109
M	16.0	32.83	
SD	11.85	25.25	

Table 3*Satisfaction with Family Life Scale Results*

Response	Pre-Intervention	Post-Intervention	<i>p</i>
SWFL			0.176
M	19.5	23.83	
SD	9.10	6.80	

Table 4*Goal Attainment Scale Results*

Families	Goal 1 Pre	Goal 1 Post	Goal 1 Change	Goal 2 Pre	Goal 2 Post	Goal 2 Change	Family Change
A	-2	0	+2	-2	0	+2	+4
B	-2	-2	0	-2	0	+2	+2
C	-2	-2	0	-2	+2	+4	+4
D	-2	-1	+1	-2	0	+2	+3
Average all families	-2	-1.25	+0.75	-2	+0.50	+2.5	+3.25