



# Occupational Performance Coaching for Caregivers of Children with Down Syndrome and Functional Feeding Difficulties



Kathleen Yee, OTD/S

Faculty Mentor: Diana Gantman-Kraversky, OTD, MS, OTR/L, AP

Site Mentors: Lan Carrico, MOT, OTR/L and Melanie Villarroel, MSOT, OTR/L

## Background

Occupational Performance Coaching (OPC) is a collaborative intervention model for caregivers and therapists to work together toward client and or family goals (Graham & Rodger, 2010). OPC's dynamic framework emphasizes client-centered care and enablement of participation in occupations within the family's everyday life (Graham & Rodger, 2009; WHO, 2001). Carrico Pediatric Therapy Inc. provides occupational therapy (OT), physical therapy (PT), and speech language pathology (SLP) services funded through Regional Center and Kaiser Permanente in San Bernardino and Los Angeles County. A needs assessment completed at Carrico confirmed literature review findings. Limited research has examined interventions specifically for individuals with Down Syndrome (DS) and functional feeding difficulties. Caregivers of children with DS often experience higher levels of stress, decreased self-efficacy, and decreased quality of life (QoL) (Dabrowska & Pisula, 2010; Philips et al., 2017). The purpose of the capstone was to examine the effectiveness of OPC for caregivers of children with DS and functional feeding difficulties.

## Needs Assessment

- Feeding is a contextually-based occupation.
- Caregiver difficulty fully implementing recommended necessary aspects of intervention at home.
- High prevalence of children with DS and functional feeding difficulties (De Graaf et al, 2015; Daunhauer et al., 2011; Rupela et al., 2016).

## Objectives

- Caregivers' participate in OPC to improve self-efficacy, improve QoL, and decrease stress.
- OTD/S to develop collaboration, clinical practice and research skills through implementation and evaluation of OPC.

## Methodology

### Mixed Methods

- Qualitative Data
  - Themes coded from OPC session notes
- Quantitative Data: Pre-post test
  - Caregiver Questionnaire
  - Goal Attainment Scaling (GAS) Goals
- Data Analysis
  - JASP (Jeffery's Amazing Statistics Program)
  - Wilcoxon signed rank, paired samples T-test
  - Exploratory research  $p < 0.10$

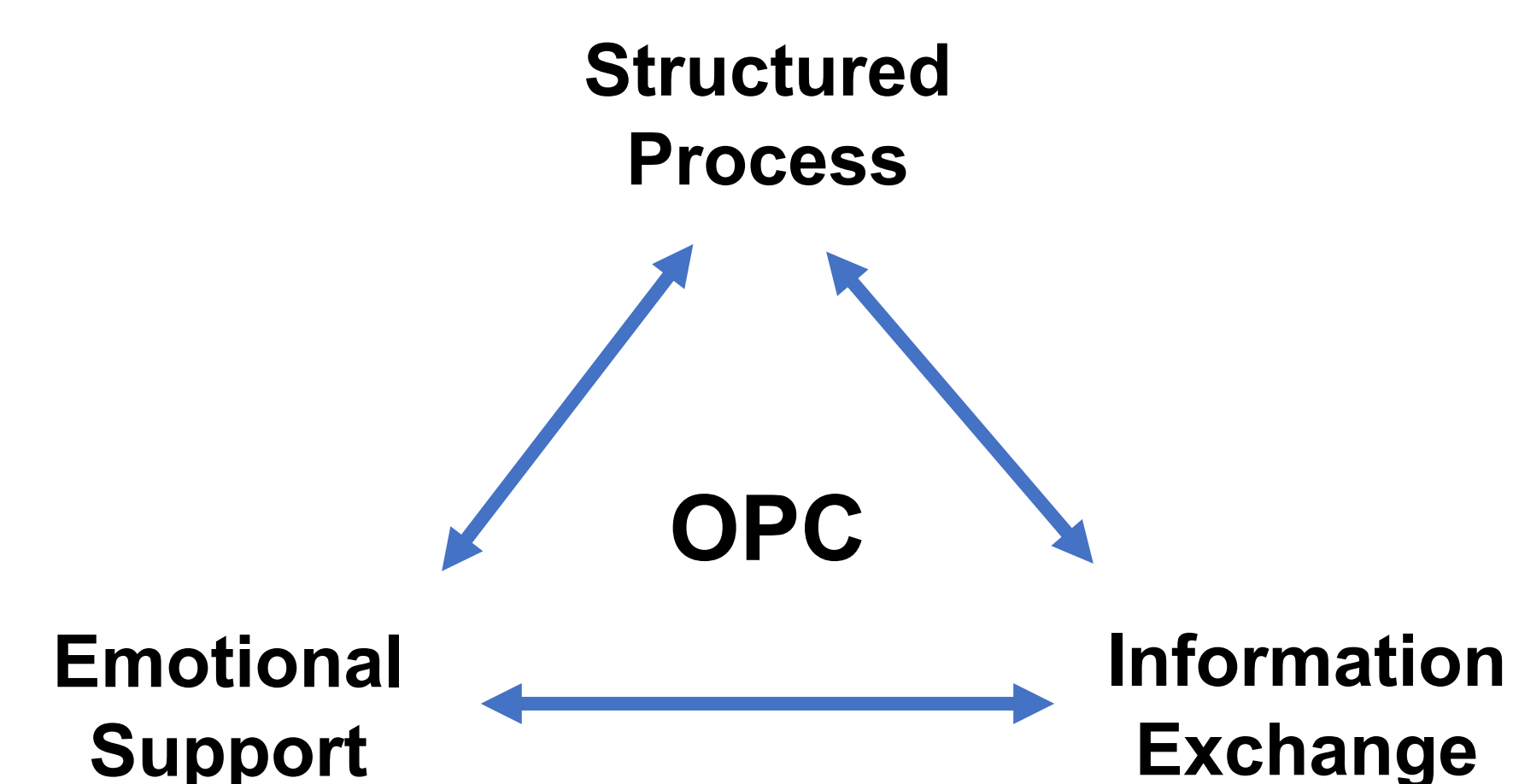
### Case Series

- Six family participants
- Client
  - Diagnosis of DS, OT feeding goals, and 2-5 years old
- Caregiver
  - Able to attend OPC session 1x/ week for 10 weeks

### OPC

- Ten weeks total
- Caregiver with OPC Coach while client with OT
- Collaborative Performance Analysis (CPA)
  - Live feeding sessions and or pre-recorded videos from home.

## OPC Domains



(Graham et al., 2010)

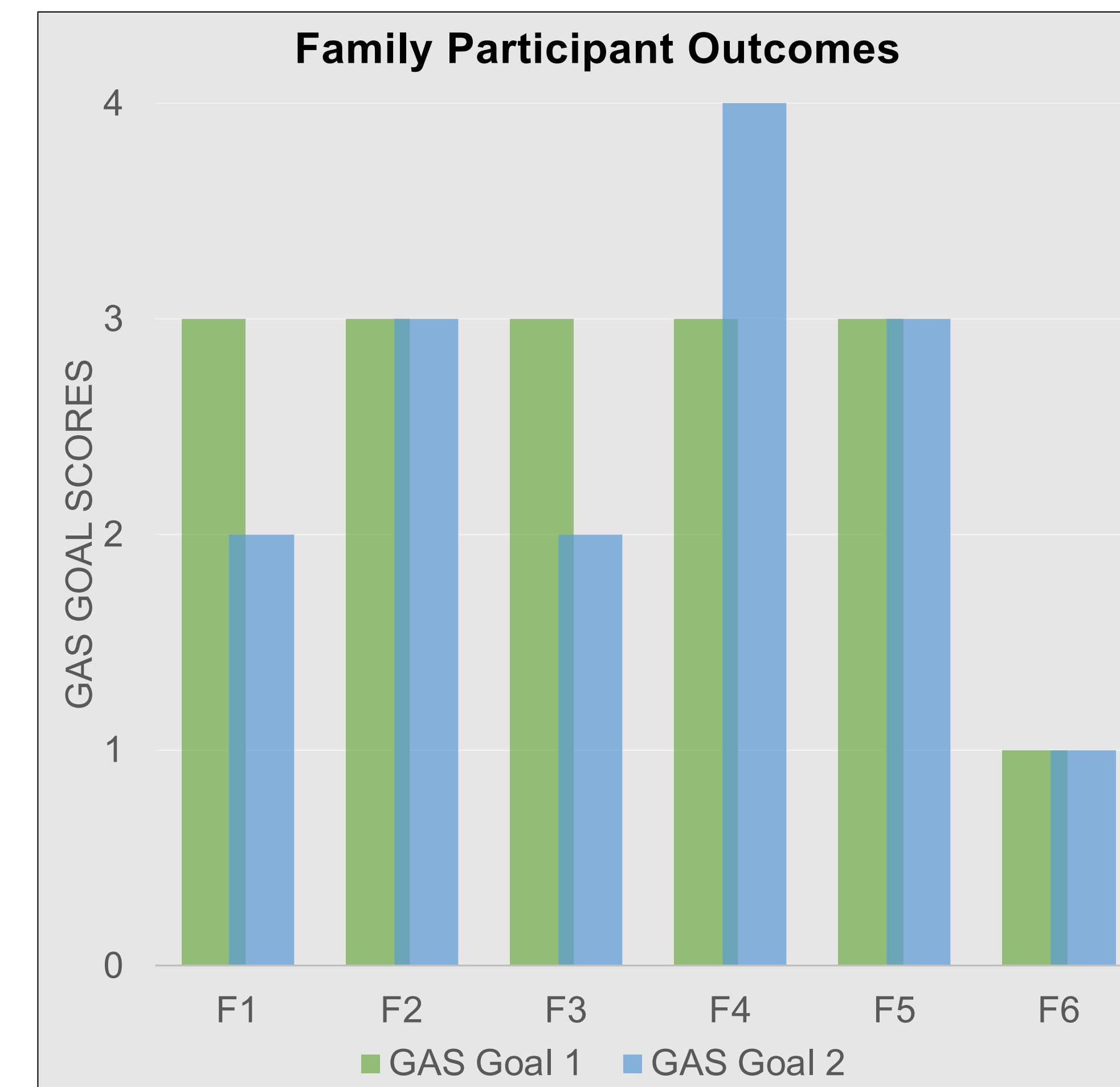
## Outcomes

### Quantitative Data

#### Caregiver Questionnaire

- Increased use and confidence using therapist recommendations at home.
- Increased self-efficacy and QoL.
- Decreased overall stress.

#### GAS Goals



Note. Nominal values of GAS indicate zero is baseline, two is expected outcome, and four is exceeding expected outcome.

### Qualitative Data

<b>Theme 1</b>	Increased participation in OPC = increased awareness of complexity of child's functional feeding difficulties.
<b>Theme 2</b>	Increased accountability = motivation to participate in OPC.
<b>Theme 3</b>	Caregivers anticipate future functional feeding difficulties but feel empowered to address challenging mealtimes.

### Deliverables

- OPC Protocol Binder
- OPC Informational Video

## Implications

1. OPC was effective in improving caregiver self-efficacy, participation, accountability and awareness.
  - Caregivers feel empowered to address future functional feeding difficulties.
  - Caregivers' anticipate future challenges with mealtimes.
2. OPC did not significantly decrease caregiver stress.
  - OPC model best practiced with third-party OPC coach in outpatient pediatric setting.
3. Caregivers do not fully disclose information with clients' assigned OTs.

## Discussion

- OPC benefits OT profession, Doctoral Experiential Internship site (Carrico), and Vision 2025 (AOTA, 2017)
- Enhance family-centered practice.
- Extend services beyond clinic, into context of families' everyday life.
- Appropriate for context-based occupations (i.e. feeding).
- Highlights the importance of an increased investment in caregiver education and training via OPC.

### Future Directions

- Regional Center proposal to fund OPC as caregiver education.
- Modify OPC to be applied through telehealth.

## Acknowledgements

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**References Available Upon Request.**