



# The Development of a Virtual Support Program for Caregivers of Children with Medical Complexities

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## Introduction

- Caregivers of children with medical complexities (CMC) have an increased experience of caregiver burnout (Teicher et al., 2022; Kehinde, 2024).
- Virtual support groups are a growing form of intervention for this population and can (Parker Oliver et al., 2017):
  - Improve social support and self-efficacy for caregivers
  - Increase feelings of emotional support and community membership, feelings of shared experience, etc. (Parker Oliver et al., 2017; Niela-Vilén et al., 2014).
- Being part of a social group can:
  - Provide sense of belonging
  - Be a source of education on relevant resources
  - Provide social support
  - Be a respite source for caregivers (Hammarberg et al., 2014).
- Occupational therapy practitioners have the capacity to explore these needs and address caregiver burden through virtual support groups to facilitate higher QoL and protect against potential burnout (AOTA, 2020).

## Methods

- 14-week project included:
  - 4 weeks of participant recruitment via survey
  - 6 weeks of program implementation
  - 4 weeks of program analysis via survey and wrap-up.
- Table 1 includes the titles of each program.

Participants:

- Caregivers of children with medical complexities completed the recruitment survey (n = 7)

Table 1. Weekly Programming Titles

Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Caregiver Burnout	Wellbeing	Self-care	Occupational Balance	Mindfulness Based Stress Reduction	Self-Advocacy and Boundaries

## References



## Results

- Two of the 7 participants completed the pre-program survey (n = 2)
- Zero of the 7 participants attended any synchronous meetings (n = 0)
- Virtual recordings of all program content was created and shared out to the initial 7 respondents after the conclusion of the program.
- Informal discussion with a caregivers led to conclusion that synchronous meetings are not supportive of caregiver needs despite flexibility and virtual format.
- Post-program survey was not distributed due all participants withdrawing via lack of attendance.
- Table 2 is a sample of qualitative responses from the pre-program survey:

Table 2. Excerpts from Participant Responses to Pre-Program Survey

Question	Participant 1 Response	Participant 2 Response
Have you experienced caregiver burnout, or are you experiencing it currently?	Somewhat	Somewhat
Describe your experience with caregiver burnout.	Being completely the only person responsible for caregiving for my child without any support from family or friends	Exhaustion, frustration in not being able to easily obtain supports, lack of close friendships as my child is a young adult and people his age are in college...he feels left behind, struggle to find "real" friendships for him.
Do you feel that you are isolated from others in your community because of your status as a caregiver?	Yes	Somewhat
Does your role as a caregiver impact your ability to take care of yourself in any capacity (e.g. missing doctor's appointments, skipping meals, overall increased stress, forgetting other responsibilities, etc)?	Yes	Somewhat
Describe how your self-care abilities are impacted by your role as a caregiver, if applicable	I don't have the financial [financial] support to do so nor the time	Again, exhausted. For years I gave up exercise and did a leave of absence from my doctorate because i was mentally exhausted after working, therapies, school, medical appointments/surgeries for my son.

## Discussion

- Seven caregivers expressed interest in the program.
  - Synchronous program delivery was unsuccessful.
  - Lack of respite care, mental health concerns, and decreased occupational balance likely impacted attendance rates (Graaf et al., 2022; Chen et al., 2023; Brown & Clark, 2017).
- Decreased Access to Respite Care
- Barriers to respite care include family resources, transportation, availability, cost, lack of knowledge of resources, and inconvenient timing (Graaf et al., 2022).
  - Decreased respite care limits caregiver ability to engage in ADLs due to overwhelming responsibilities related to care of their dependents.

- Mental Health Concerns in Caregivers of CMC
- Caregivers experienced decreased mental health:
    - 32% reported having average mental health
    - 53% reported moderately below average mental health
    - 15% reported severely below average mental health (Nathwani et al., 2024)
  - It is known that decreased mental health impacts ability to engage in occupations across a variety of areas including self-care (SAMHSA, 2024).

- Decreased Occupational Balance
- The presence of children in a home impacts caregiver occupational balance.
  - There is a statistically significant difference in the impact on occupational balance and family quality of life for caregivers of CMC as compared to caregiver of typically developing children (Dhas et al., 2023).

- Limitations & Future Suggestions
- Limited research regarding caregivers of CMC.
  - Increased barriers to participation for this population.
  - Explore the use of virtual platforms with asynchronous engagement
  - One-on-one interviews with participants to gather information about preferred topics for group programming.
  - Coordinate schedules based on school system breaks and schedules to maximize time caregivers might have available to engage in any synchronous programming.

## Conclusion

- Caregivers of CMC are seeking support in relation to the experience of burnout.
- A synchronous support group was difficult for caregivers to attend.
- If caregivers do not have support in the care of their dependents, self-care resources are difficult to access despite their availability.

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