



Exceptional Caregivers: A Support Group for Caregivers of

Adults with Disabilities

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Introduction

- As of 2020, there are 6.1 million informal caregivers in the United States providing care to adults between the ages of 18 and 49
- Additionally, individuals diagnosed with Intellectual or Developmental disabilities are living longer, increasing the length of time that caregivers are providing care, with many caring for their children into late older adulthood
- Long-term caregiving has significant effects on the caregiver’s physical and psychological health and well-being impacting overall quality of life
- The Exceptional Foundation is a non-profit organization that provides social and recreational services to adults and children with disabilities
- This study aims to (1) identify the needs of caregivers of adults with disabilities and (2) develop a program that addresses these needs to promote caregiver well-being for future implementation at The Exceptional Foundation

Methods

Review of Current Literature:

- Databases searched: CINAHL, ERIC, and Scopus
- Concepts searched: caregivers broadly, caregivers of adults with disabilities and caregiver burden
- Search Terms: (caregiver OR informal caregiver OR family caregiver OR carer) AND (adults AND disabilities) AND (caregiver burden OR caregiver stress OR caregiver strain OR caregiver burnout)
- Search filters: English language and published between 2013 and November 2023
- Hand search of references of selected articles was carried out
- 33 articles were selected based on relevance to the present study

Data Analysis:

- Once selected, each article was analyzed for relevant findings, concepts, constructs, and variables.
- NVivo, a qualitative analysis software, was used to categorize or “code” the articles to identify recurring constructs
- Constructs that appeared in more than six articles or 20% were included in the development of this program

Results

Findings:

- Six constructs were identified that appear in more than six articles or 20%.
- Caregiver burden – 31 articles (~94%)
 - Psychological well-being or mental health – 26 articles (~79%)
 - General health – 18 articles (~55%)
 - Stress – 14 articles (~42%)
 - Coping – 12 articles (~36%)
 - Self-care – 7 articles (~21%)

Program Design:

- Four one-hour sessions were developed to address these needs
- Program curriculum (described in the table below) includes education on the topics of caregiver burden and the importance of wellness promotion, self-care, and stress management/effective coping.
- Activities and facilitated discussion are used to support participants in making changes that promote their physical and psychological health and wellness.

Session (Duration)	Educational Concepts	Activity	Expected Outcomes
Session 1: Caregiver Burden Length: One hour	1. Define caregiver burden 2. Educate on the physical and emotional health consequences of caregiver burden 3. Define wellness 4. Describe the domains of wellness	Wellness wheel activity to assess wellness in each domain and discuss possible areas of imbalance	Participants will assess their health and wellness and identify areas of imbalance .
Session 2: Self-Care Length: One hour	1. Define self-care 2. Educate on the importance of self-care and negative health consequences of neglecting these practices 3. Provide practical examples of self-care in each domain of wellness	Creating a self-care plan including: 1. Identifying self-care practices in each domain of wellness 2. Recognizing areas of wellness that may need improvement 3. Recognizing potential supports (people or resources) that will be helpful in the implementation of the self-care plan	Participants will develop a self-care plan that they can implement into their daily life to promote self-care practices.
Session 3: Stress Management and Coping Skills Length: One Hour	1. Educate on the negative health effects of stress 2. Define coping 3. Describe effective coping skills 4. Describe ineffective coping skills	Practice stress management techniques including: 1. Box breathing 2. Diaphragmatic breathing 3. 5-4-3-2-1 mindfulness exercise 4. Journaling 5. Progressive muscle relaxation	Participants will experiment with relaxation techniques to promote use of effective coping skills when dealing with stress.
Session 4: Stress Management and Coping Skills continued Length: One hour	1. Review concepts from session 3 (stress and coping) 2. Explain the importance of goal setting 3. Educate on developing SMART goals	1. Identifying signs and symptoms of stress worksheet 2. Circle of control worksheet 3. Coping skills worksheet 4. SMART goals worksheet	1. Participants will explore their relationship with stress by: recognizing signs of stress, identifying stressors, and examining their use of coping skills. 2. Participants will also develop a health-related SMART goal based on the topics discussed in the program.

Discussion

Stakeholder Feedback:

- The program curriculum was reviewed by the Director of Partnerships and Outreach at The Exceptional Foundation, Robbie Lee
- The protocol was felt to be appropriate and valuable to the organization and did not require any revisions

Implications for Practice:

- The findings shed light on the impact of long-term caregiving as well as the current needs of caregivers
- This information is beneficial to occupational therapy practitioners (OTPs) when working with caregivers
- OTPs should educate caregivers on the importance of taking care of their own health and focus interventions on preventing or minimizing the negative effects of caregiver burden through the promotion of health and wellness
- Future research should aim to identify the most effective interventions to promote caregiver health and well-being and decrease caregiver burden

Discussion continued

Limitations:

- Researcher was unable to collect formal data, so no information was gathered from the caregivers at The Exceptional Foundation
- Due to the time constraints of the semester, the student was unable to pilot the program at The Exceptional Foundation

Conclusion

- Due to the rise in informal caregivers, it is essential for healthcare professionals to understand the impact of this role and the needs of this population
- Caregiving affects caregivers physical and psychological health and leads to overall decreased quality of life
- Further research is imperative to determine the most effective interventions for supporting caregivers and combat the negative effects of caregiving

References

Abramson, T. A. (2015). Older Adults: The “Panini Sandwich” Generation. *Clinical Gerontologist*, 38(4), 251–267. <https://doi.org/10.1080/07317115.2015.1032466>

Byram, E. (2018). Late-Life Challenges in Caregiving for an Adult Child with a Developmental Disability. *Generations (San Francisco, Calif.)*, 42(3), 9–14.

Caregiving in the U.S. 2020: A focused look at family caregivers of Adults Age 18-49 . (n.d.). https://www.caregiving.org/wp-content/uploads/2021/05/AARP1339_RR_Caregiving18to49_5081.pdf

Dawson, F., Shanahan, S., Fitzsimons, E., O’Malley, G., Mac Giollabhui, N., & Bramham, J. (2016). The impact of caring for an adult with intellectual disability and psychiatric comorbidity on carer stress and psychological distress. *Journal of Intellectual Disability Research*, 60(6), 553–563. <https://doi-org.uab.idm.oclc.org/10.1111/jir.12269>

Fernández-Ávalos, M. I., Pérez-Marfil, M. N., Ferrer-Cascales, R., Cruz-Quintana, F., Clement-Carbonell, V., & Fernández-Alcántara, M. (2020). Quality of Life and Concerns in Parent Caregivers of Adult Children Diagnosed with Intellectual Disability: A Qualitative Study. *International Journal of Environmental Research and Public Health*, 17(22), 8690-. <https://doi.org/10.3390/ijerph17228690>

González-Fraile, E., Domínguez-Panchón, A. I., Berzosa, P., Costas-González, A. B., Garrido-Jimenez, I., Rufino-Ventura, D., López-Aparicio, J. I., & Martín-Carrasco, M. (2019). Efficacy of a psychoeducational intervention in caregivers of people with intellectual disabilities: A randomized controlled trial (EDUCA-IV trial). *Research in Developmental Disabilities*, 94, N.PAG. <https://doi-org.uab.idm.oclc.org/10.1016/j.ridd.2019.103458>

Grey, J. M., Totsika, V., & Hastings, R. P. (2018). Physical and psychological health of family carers co-residing with an adult relative with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31, 191–202. <https://doi-org.uab.idm.oclc.org/10.1111/jar.12353>

Acknowledgement & Contact information