



EVALUATING A FACEBOOK GROUP SELF-CARE INTERVENTION FOR CAREGIVERS OF CHILDREN WITH DISABILITIES

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Background

Millions of family members in the United States provide assistance with activities of daily living and/or medical tasks for a loved one, thus serving as family caregivers.¹ Around half of family caregivers experience chronic physical and psychological symptoms which impact their caregiving abilities.^{1,2}

Family caregivers are critical for supporting children with developmental disabilities (DD). These caregivers are better able to support the physical, cognitive, socio-emotional, behavioral, and academic development of the children in their care when they are physically and psychologically healthy.³ However, such caregivers are also at increased personal risk for adverse physical and mental health outcomes related to chronic stress compared to those with children without DD.^{4,5} Stress among family caregivers often stems from strains associated with caregiving demands, such as child behavioral challenges or medical needs, financial burden, relationship strain, physical demands of caregiving, and perceived social isolation.^{3,6}

It is important for caregivers of children with DD to engage in self-care to prevent and reduce these risks. Personal self-care has shown to combat the effects of chronic stress from caregiving, yet many caregivers experience barriers to engaging in self-care.⁷ Caregivers report being better able to engage in self-care with the support of family, friends, or peers.⁸ In addition, internet-based peer support groups can provide social and emotional support for caregivers.⁹ This brief summarizes a pilot [study](#) of a health-promoting self-care intervention delivered via Facebook group for caregivers of children with DD.

The Intervention

The intervention was piloted with 34 caregivers of children with DD during the fall of 2019 and lasted 8 weeks. It was delivered asynchronously via a “secret” Facebook group, meaning that only the researchers and the participants were able to search for or join the group. During each of the 8 weeks, participants a) completed a single-item scale as a check-in on progress towards their identified self-care goals, and b) read and “reacted” (e.g., liked) to at least one post or comment (this could be either a researcher or participant post).

The key features of the intervention included:

- Researcher-posted weekly prompts and brief activities (e.g., a link to a video to watch, article to read, resource to try).
- Personal goal setting around self-care needs (e.g., identifying a goal to eat more fruits and vegetables or get more sleep, monitoring progress toward their goal each week). Social support provided by other caregivers participating in the Facebook group intervention.

Below is an example of a researcher prompt and brief activity around stress management within the topic of psychological health:

Topic	Example Researcher Post
Psychological Health – Stress Management	Whether you're familiar with mindfulness and use it, have heard the term but don't know what it means, or have never heard of the concept, this website provides information, resources, and videos about ways all of you can incorporate mindfulness into your life! https://www.mindful.org/meditation/mindfulness-getting-started/

Topics of focus for self-care goals and intervention content (i.e., researcher and participant posts) were:

- Physical health (e.g., nutrition, exercise, sleep) in weeks 1-2,
- Psychological health (e.g., stress management, anxiety, depression) in weeks 3-4,
- Social health (e.g., social support, relationships) in weeks 5-6, and
- Work health (e.g., balancing work/school with family, time management) in weeks 7-8.

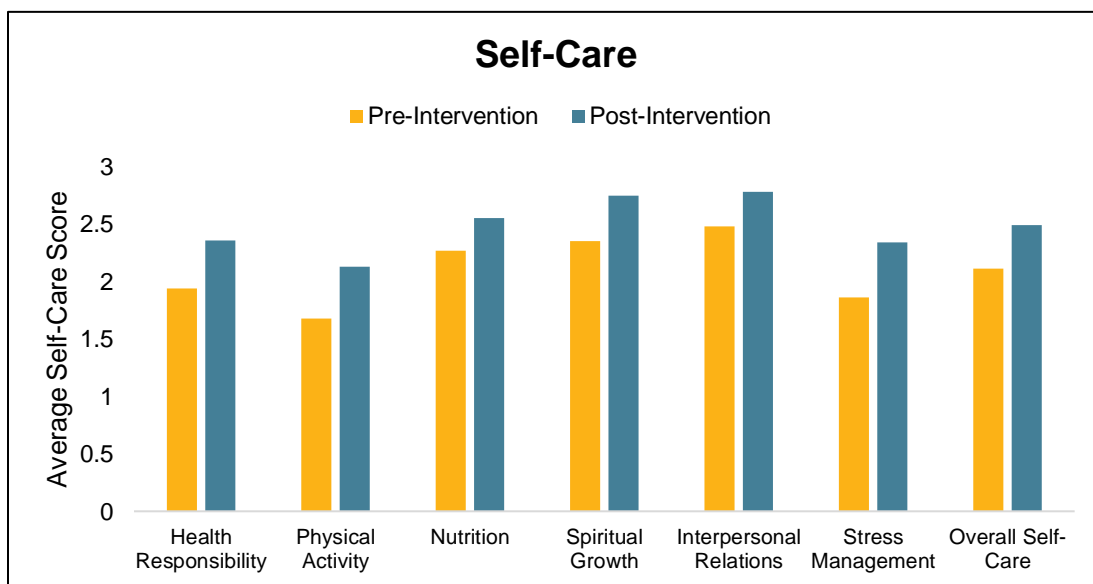
Key Findings

Stress

- From pretest to posttest, there was a small but statistically significant decrease in participants' perceived stress following the 8-week intervention.

Self-Care

- Participant reports on the [Health-Promoting Lifestyle Profile II](#), on which the frequency of self-care behaviors are rated on a scale from 0 (never) to 3 (routinely), indicated that caregivers' levels of self-care showed a small but statistically significant increase from baseline levels at the end of the 8-week intervention.
- As shown in the graph below, participants reported the most improvement with respect to stress management, spiritual growth, and physical activity.



Usability

Overall, participants rated the intervention positively in terms of its usability. In particular, they generally agreed that the intervention was reasonably easy to use, not too time-intensive, and did not require too much preparation; that they understood how to use the intervention; and that they were enthusiastic about the intervention.

Notably, 85% of participants were retained throughout the 8-week intervention, which speaks to the usability.

Implications

Initial findings indicate that a health-promoting self-care intervention delivered via Facebook group shows promise as a usable (easy to use, effective, satisfying) method to support caregivers of children with DD in reducing stress and increasing self-care. These results suggest that caregivers of children with DD can benefit from access to information and peer support without direct support from an interventionist. The structure of this intervention mimics that of existing Facebook support groups, highlighting a potential mechanism that professionals may tap into when considering how to best provide indirect support to caregivers of children with DD.

Additional Resources to Support Caregiver Well-Being

Caregiver Guide for Special Needs

Gives information and advice to help caregivers overcome challenges and understand the unique needs of people with disabilities.

Center for Parent Information and Resources

Lists articles and information about disabilities; provides resources, support groups, and services.

Caregiving Tips for Families of People with Disabilities

Provides helpful tips for family caregivers of people with disabilities.

University of Connecticut Caregiver Study: Resources

Links to various papers with information and resources for caregivers of children with disabilities.

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¹ Chafouleas, S. M., Iovino, E. A., & Koriakin, T. A. (2020). Caregivers of children with developmental disabilities: Exploring perceptions of health-promoting self-care. *Journal of Developmental and Physical Disabilities, 32*(6), 893–913. <https://doi.org/10.1007/s10882-019-09724-x>.

² Family Caregiver Alliance (2016). *Caregiver statistics: Demographics*. <https://www.caregiver.org/resource/caregiver-statistics-demographics/>

³ Goudie, A., Nacisse, M., Hall, D.E., & Kuo, D.Z. (2014). Financial and psychological stressors associated with caring for children with disability. *Families, Systems, and Health, 32*, 280-290.

⁴ Gallagher, S. & Whiteley, J. (2012). Social support is associated with blood pressure responses in parents caring for children with developmental disabilities. *Research in Developmental Disabilities, 33*, 2099-2105.

⁵ Schulz, R., & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*, 27.

⁶ Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations, 65*, 207-224.

⁷ Acton, G. J. (2002). Health-promoting self-care in family caregivers. *Western Journal of Nursing Research, 24*, 73-86.

⁸ Pender, N. J., Murdaugh, C. L., & Parsons, M. (2015). *Health promotion in nursing practice* (7th ed.). Pearson.

⁹ Niela-Vilen, H., Axelin, A., Salantera, S., & Melender, H. (2014). Internet-based peer support for parents: A systematic integrative review.