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Kylee Hall

University of St. Augustine for Health Sciences, k.hall1@usa.edu

Helen Carey

University of St. Augustine for Health Sciences, hcarey@usa.edu

Lauren Webb

Les Turner ALS Foundation

Lisa Griggs-Stapleton

University of St. Augustine for Health Sciences, lstapleton@usa.edu

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Addressing ALS Caregiver Needs: An Occupation-Based Caregiver Education Program

Kylee Hall, OTS; Lisa Griggs-Stapleton, PhD, OTR; Helen Carey, Ph.D, MSc Adv OT, OTR; Lauren Webb, LCSW

BACKGROUND

Individuals living with Amyotrophic Lateral Sclerosis (ALS) will likely require significant support with essential needs and daily occupations as the disease progresses (MedlinePlus, 2020). Informal family caregivers are often the main support system for an individual with ALS and they are frequently underprepared to provide care. Occupational therapy practitioners work with individuals with ALS and their caregivers to provide support that facilitates optimal performance with daily occupations.

PROBLEM

Approximately 80% of home care services are provided by informal family caregivers (ALS Association, 2020). Adult and youth caregivers report they need support so they can provide care effectively.

PURPOSE

To develop an occupation-based caregiver education program for ALS caregivers.

Outcome objectives:

- Conduct a needs assessment to understand specific caregiver needs
- Develop a caregiver education program that addresses specific caregiver needs
- Implement a caregiver education program that addresses specific caregiver needs
- Determine program outcomes through a post training program survey

METHODS

Ten caregivers from the Les Turner ALS Foundation and social media support groups were invited to participate in the program.

Virtual interviews were completed to determine caregiver needs in order to select program topics. A post-training survey was completed to determine program outcomes after caregivers completed the program.

- 10 caregivers participated in the needs assessment
- 10 caregivers completed the program
- 5 caregivers participated in the post-training survey

Needs Assessment: Participants were asked open-ended questions about their needs as a caregiver. A thematic analysis was completed to determine the top caregiver needs.

Needs Found:

- Education on how to advocate for yourself as a caregiver
- Education on how to manage changing relationship dynamics
- Education on how to prevent and handle caregiver burnout
- Education on how to support children and youth
- Education on how to find financial support

Post Training Survey: Participants completed a post-training survey and/or interview. Caregivers were asked to provide feedback and recommendations to improve the program.

Program Outcomes:

- 100% of participants approved of the topics selected for each guide
- 100% of participants approved of the language used in each guide
- 100% of participants approved of the length of each guide
- 100% of participants approved of the style of each guide
- 100% of participants found the program beneficial

RESULTS

PROGRAM COMPONENTS

Program Format:

This program adds a new component to the Les Turner ALS Foundation's already established online educational programs. The foundation had a program for people living with ALS but did not have a program for caregivers prior to this project.

The program is set to launch to the general public in 2022. Caregivers will be able to access the program from the Les Turner ALS Foundation website.

Program Topics:

- ALS & Caregiver Self-Care
- ALS & Relationships
- ALS & Children, Youth, and Young Adults
- ALS & Caregiver Rights

Program Guides Include:

- Positive and uplifting tone
- Quotes from other caregivers
- Graphics
- Resources for caregivers

General Program Goals:

- Increase caregiver confidence and competence
- Increase quality of life for the caregiver and person living with ALS
- Enable the caregiver to effectively manage anxiety and stress to decrease caregiver burnout
- Promote engagement in occupations that support valued life roles

Theoretical Frameworks:

- Person-Environment-Occupation-Performance (PEOP)
- Model of Co-Occupation

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References

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 MedlinePlus. (2020). *Amyotrophic lateral sclerosis (ALS)*. Retrieved December 4, 2020, from <https://medlineplus.gov/ency/article/00688.htm#:~:text=In%20ALS%2C%20motor%20nerve%20cells,The%20condition%20slowly%20gets%20worse>