



UNIVERSITY OF NEW ENGLAND
Center for Excellence
in Collaborative Education

Caring for Caregivers of a Loved One with ALS

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Abstract

Goal of this project was to supply caregivers that attended the Caring for Clients with Amyotrophic Lateral Sclerosis (ALS) workshop with a care package. This care package provided tools and resources to help relieve stress and ease the burden that caregivers may be experiencing by promoting self-care. Fifteen packages were distributed after the facilitation of an all-day workshop on November 16, 2019. Each recipient was sent home with a survey that was to be sent back a month later to provide feedback about the contents.

Background

- Caregiver burden= stress placed on primary caregiver for a loved one with a medical condition (Adelman et al., 2014)
 - Not professional caregivers (Adelman et al., 2014)
- High levels of burnout and stress (Adelman et al., 2014)
- Challenges:
 - Finances, impact of healthcare for the disease, increasing demands of condition (Adelman et al., 2014)
- Caregivers often struggle to take adequate time for themselves, their health, and their own interests (Adelman et al., 2014)
 - Social isolation

Methods



Care Packages



Fig 1: Images of care package final product; A. Incense and burner, B. Care package, C. Eye mask, D. Bookmark/ reference list, E. Coloring book and colored pencils, F. Exercises packet, G. Yoga poses packet

Results

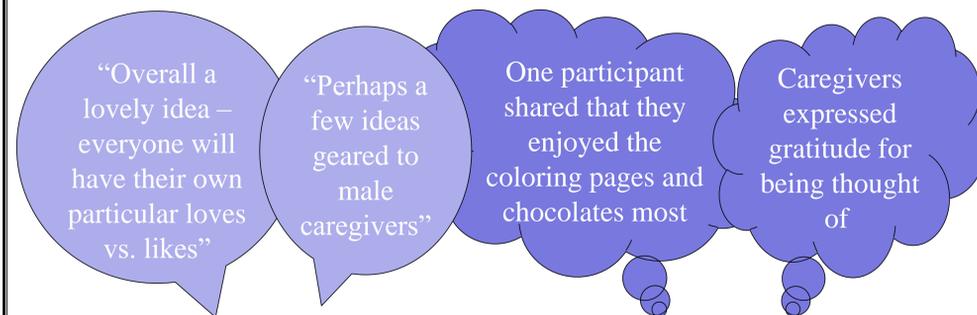


Fig 2: Quotes from the ALS Caring For Caregivers- Participant Evaluation Form.

Fig 3: Consensus from participants that attended support group.

Rate of Helpfulness for Each Items in Care Packages

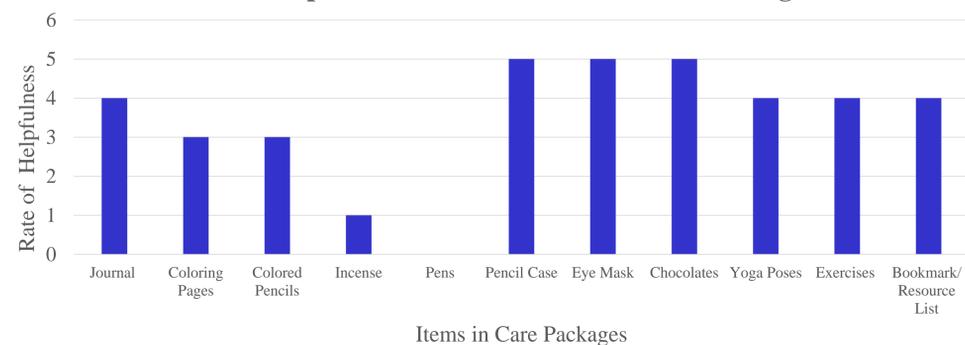


Fig 4: Data from participant evaluation form based on results from Likert Scale on a scale of; not helpful at all-1, slightly helpful-2, somewhat helpful-3, very helpful-4, extremely helpful-5 (n=1). Data was compiled to determine the percentage of helpfulness of care packages, and it was concluded that the overall care package as an entirety was 92% in some way helpful.

Reflections

The burden placed on caregivers is significant and has impacts on emotional, mental, and physical health. The ability to provide care packages to caregivers of a loved one with ALS was truly a meaningful experience. The project would have benefited from a longer timeline to complete the project application process and gain approval from the IPEC board. Also, a pre-survey given to participants to gain a greater knowledge of participants' interests to make the care packages more client-centered would have improved the project outcomes. Overall, it was a beneficial experience to work on an interdisciplinary team, as we all brought unique and diverse perspectives.

Future Considerations

- More inclusive care packages (male caregivers and younger caregivers)
- Determine how much time caregivers take for themselves (Poll Everywhere)
- Provide caregivers with education and rationale of each item
- Collect data through online survey (Survey Monkey)
- Gather more information ahead of time of client demographics and interests
- More conscious of time requirements

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References

References available upon request