



Bridging the Gap: Essential Resources for TBI Caregiver Well-Being

Author: Vanessa Rivera OTD/S

DCE Site Mentor: Christine Weaver OTR/L, CLCP, CBIS, C/NDT

Faculty Mentor: Valerie Perry OTDR/L

West Coast University, Center for Graduate Studies



Description of DCE Site

- Neuropraxis is a home & community brain & spinal cord injury rehabilitation program.
- Founded in 2015 by Christine Weaver OTR/L.
- Serves the entire California region, those who are medically stable, 13-years of age or older, & Rancho Level IV or above.

Needs Assessment Results

1. Caregiver Education
2. Caregiver Social Support
3. Comprehensive California TBI Resource Guide

Student Learning Objectives

1. I developed & implemented a telehealth caregiver support program to improve caregiver overall well-being.
2. I acquired evidenced based knowledge of the TBI community by completing & disseminating an online comprehensive TBI resource guide.
3. I acquired improved leadership & advocacy skills pertaining to outreach to promote awareness of occupational therapy services (OT) & roles for community based TBI caregivers.

Literature Review

Importance of Time Efficient Caregiver Support Groups

- Caregiver support groups equipped with video conferencing, instant messaging, emails, and self-paced online activities have been found to maximize psychosocial outcomes for caregivers (Damianakis et al., 2015; Marshall et al., 2019; Rietdijk et al., 2012)

Caregiver Well-Being Supports Survivor Recovery Outcomes

- The survivor's emotional and behavioral shifts can significantly strain the caregivers' well-being. Survivors who receive care from caretakers with high reported caregiver burden demonstrate heightened impairment in their neuropsychological functioning. (De-Torres et al., 2022; Kreitzer et al., 2018; Lehan et al., 2012; Marshall et al., 2019)

Need for Support System Focused Interventions & Resources

- Those who uphold familism or have limited access to resources and support, are at higher risk of caregiver burnout and less likely to provide effective care. The utilization of adaptive leadership from caregivers is essential in providing effective client centered care for TBI survivors. Adaptive leadership requires collaborative problem-solving and a growth mindset to find solutions and learn from mistakes throughout the TBI chronic disease process. (Baker et al., 2021; Heeter et al., 2011; Kreitzer et al., 2018; Lehan et al., 2012; Marshall et al., 2019; Rietdijk et al., 2012)

Scholarly Deliverables

1. A Six Week Online Caregiver Support Group
2. Six Publicly Accessible Caregiver Educational Modules
3. Social Media Infographics for Module Key Points
4. Two Online Communities to Promote Caregiver Connection & Awareness of Resources
5. DCE Site Support Group Training Manual for Occupational Therapy Students
6. An Online Brain Injury Resource Guide
7. A Webinar on "Occupational Therapy's Role in Supporting TBI Caregiver Well-Being"

Project Description

Guiding Frame of Reference

- Resiliency Model of Family Stress, Adjustment, and Adaptation

Project Purpose

- Improve caregiver well-being through accessible resources and support:
 - A 6-week online support group equipped with open discussion, weekly modules, and activities
 - One community based presentation
 - One comprehensive brain injury resource guide

Program Implementation Schedule

- **Week 1:** Managing TBI Behaviors & Cognitive Deficits
- **Week 2:** Communication Techniques & Managing Conflict
- **Week 3:** Tips in Including Self-Care into Your Routine
- **Week 4:** Managing Stress and Negative Emotions
- **Week 5:** How to Support Their Return to Previous Roles
- **Week 6:** Goal Setting and Problem Solving Techniques

Utilized Communication Platforms

- YouTube
 - Over 600 views for modules 1 - 6
- Facebook and Reddit Support Group Community
 - Over 60 collective members

Evaluation Method

Quantitative Data Collection

- Pre-Posttest Surveys for Modules & Webinar
 - 4 point likert scale (1 = no idea, 2 = somewhat little, 3 = general knowledge, 4 = strong understanding)
- One embedded survey within the resource guide

Qualitative Data Collection

- Two Semi-Structured Support Group Interviews

Project Outcomes

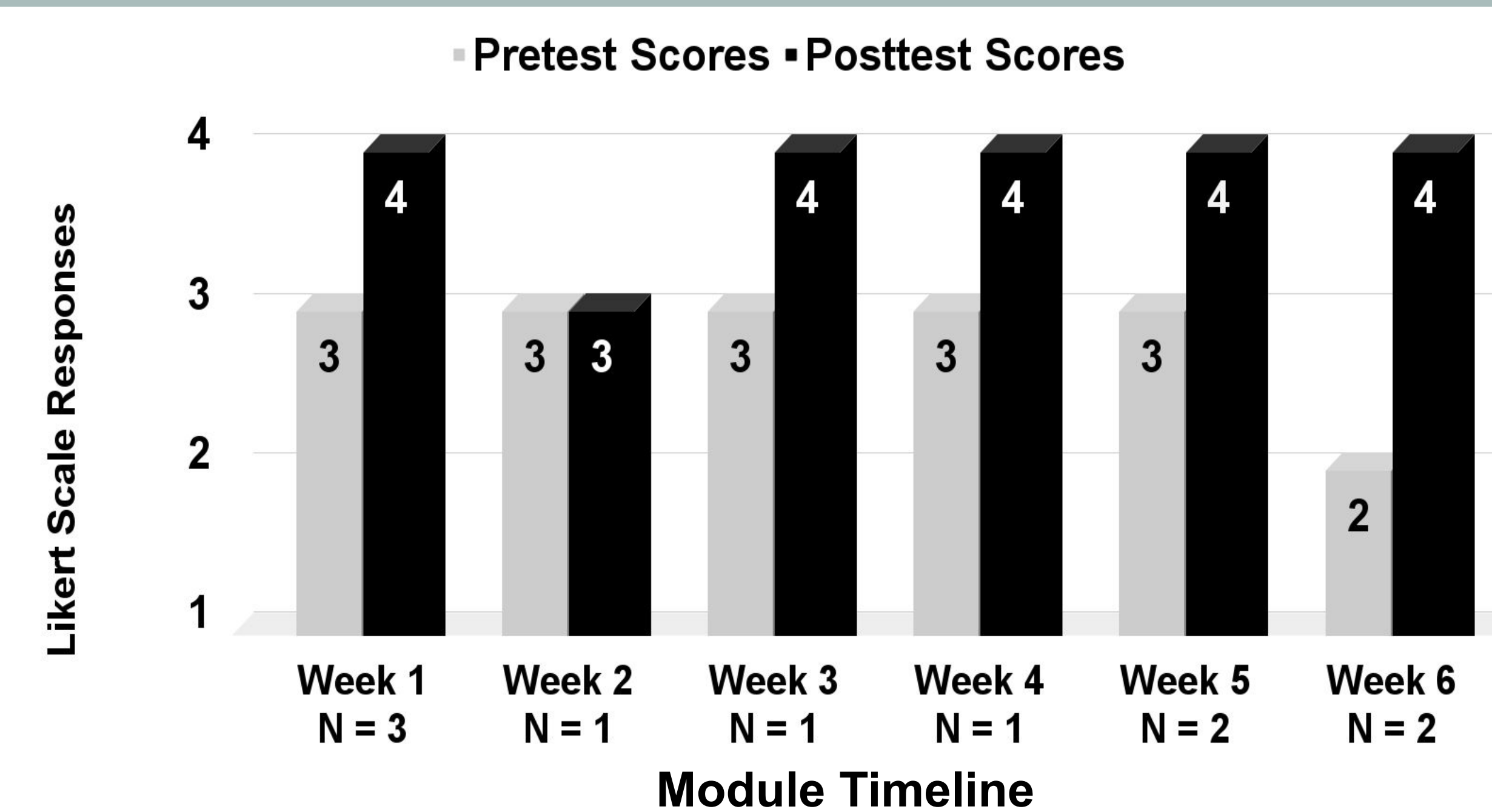
Demographics

- N = 20 signed up for the support group, N = 5 attended live sessions
 - 1 wife and 4 mothers of a TBI survivor
 - 2 participants viewed 6/6 modules (1 wife and 1 mother)
 - Caregiver experience ranged from 14 months - 3 years
- N = 16 signed up for the webinar session, N = 7 attended live session

Qualitative Support Group Interview Data

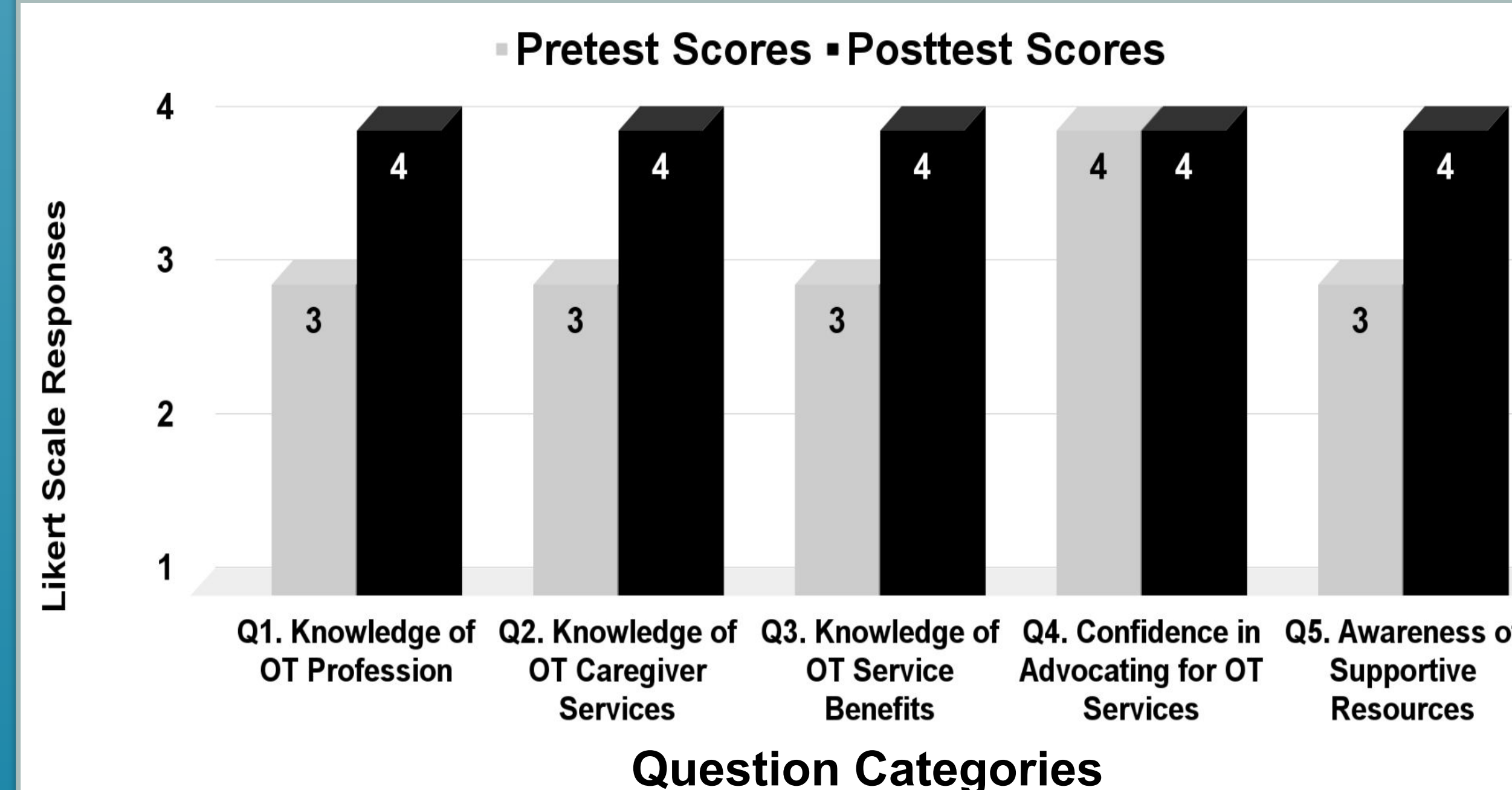
- Theme 1**
Improved Understanding of TBI Recovery
 - N = 2 participants
 - 1 wife and 1 mother
 - 5 themes
 - 13 sub-themes
- Theme 2**
Awareness & Use of Supportive Resources
 - Overall participants found connection to those with similar experiences, practical tools, guidance, improved patience and a positive outlook on their caregiving experience.
- Theme 3**
Positive Change to Caregiving Approach
- Theme 4**
Safe Space to Share TBI Caregiver Experience
- Theme 5**
Practical Strategies for Managing Care

Quantitative Module Data



Note. (N = 5) Caregiver understanding of supportive techniques improved following 5/6 modules. Module 6 demonstrates the largest improvement in caregiver knowledge from "somewhat little" to "strong understanding".

Quantitative Webinar Data



Note. (N = 2) Results appear to demonstrate improvement in 4/5 webinar learning objectives for the live webinar session.

Discussion

- The week 6 module indicated the largest overall change in caregiver understanding of adopting a growth mindset, creating SMART goals for themselves or their care recipients, and implementing collaborative problem-solving techniques.
- Exposure to the week 3 module also demonstrated a change in 2 learning objectives: caregiver understanding how to process ambiguous loss and find acceptance in their loved one's recovery.
- Following the webinar, participants reported an improved understanding of the OT profession, how OT interventions can benefit their well-being and their awareness of supportive resources.
- The findings align with the current literature on effective interventions that support caregiver well-being through education in adaptive leadership principles, emotion management, problem-solving techniques, goal-setting, and supportive resources.

Future Implications

- Standardized evaluation is needed to validate the project's findings.
- A larger sample size and year-long implementation of the support group can identify long-term benefits and carryover.
- Future OT-led presentations should educate the multidisciplinary team on the importance of connecting survivors and caregivers to supportive resources during the early stages of recovery.
- Due to the TBI chronic disease process, future support groups and education implementation should be curated for long-term caregivers with more than 3 years of experience.
- Collaboration from neurologists and case managers can supplement future support group curriculum and incentivize future participation.

Conclusion

- The project addressed the multi-dimensional needs and well-being of TBI caregivers under the Resiliency Model of Family Stress, Adjustment, and Adaptation.
- The findings adds to the literature on the need for OT interventions and time-efficient support groups for TBI caregivers.
- Continued execution of OT interventions can provide caregiver's evidence-based techniques and resources to support their well-being as adaptive leaders within the brain injury recovery.

References



Deliverables

