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## **Psycho-Emotional Education for Occupational Therapists Supporting Individuals Assuming the Role of Family-Caregiver for People With a Traumatic Brain Injury (TBI)**

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# Psycho-Emotional Education for Family-Caregivers of an Individual With a TBI



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## Background

### Traumatic Brain Injury (TBI)

- TBI is a non-degenerative debilitating brain injury caused by an external force (Qadeer et al., 2017).
- TBI ranges from mild to severe and is estimated to impact 1.4 million people per year. TBI can cause lifelong disability, changes in personality, and performance deficits (Carlozzi et al., 2015; Qadeer et al., 2017).
- Individuals who sustain a TBI are faced with a chronic health condition that may require long term care and support (Hart et al., 2018).

### Impact of TBI on Caregivers

- Caregivers of individuals who have sustained a TBI are faced with many challenges and personal changes to their daily life.
- Often, much of the focus of rehabilitation is on the patient's recovery and facilitating a safe return home, yet little attention is paid to the caregivers who play a vital role in the success of the patient.
- The changes for the family members who assume this new role of caregiver can cause extreme emotional distress, and family system dysfunction (Carlozzi et al., 2015).
- When the caregiver's needs go unmet, the TBI survivor's recovery can be negatively impacted (Niemeier et al., 2019).
- Taking on this new role has been shown to decrease the family-caregiver's quality of life as well as potentially increase the risk of depression, anxiety, and grief (Saban et al., 2016).

### Importance of the Problem:

- The National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP) reported an increased in unpaid family caregivers since 2015 (NAC & AARP, 2020).
- In 2020 it is estimated that there were 53 million family caregivers in the United States, and of those, 23% reported their health had declined due to caregiving (NAC & AARP, 2020).

## Literature Review

### PICO Question:

How can occupational therapists (OTs) improve confidence and competence for family members, assuming the role of caregiver, for a loved one following a TBI.

### Themes Identified in the Literature:

- Ambiguous Loss
  - Describes when a family member is present physically, yet is psychologically changed, specifically in relation to their personality, thinking, and memory (Boss, 2016; Petersen & Sanders, 2015).
- Grief and Grieving
  - Caregivers are providing care in an environment of ambiguity. Thus, they are left to keep their feelings of grief and loss hidden, only creating increased psychological pain (Boss, 2016).
- Importance of Validating Caregivers' Emotions
  - Validating tough emotions can help manage stress and anxiety and improve self-efficacy (Kreutzer et al., 2016).
- Coping Strategies
  - Coping strategies that focused on stress management, productive problem-solving skills, and increased perceptions of self-efficacy were shown to decrease caregiver stress and anxiety, and better prepare them for their new role (Backhaus et al., 2010).
- Importance of Caregiver Resources
  - Providing community resources and information related to support systems and respite support enable the caregiver to take on the new and unfamiliar role while maintaining their health and well-being (Gan et al., 2010; Suntai et al., 2021).

## References



## Methods

### Hypothesis:

A two-hour educational seminar regarding the psycho-emotional needs of family-caregivers for people with a TBI will

- Increase practitioner confidence to address the psycho-emotional needs of an individual assuming the role of family-caregiver
- Increase confidence in ability to explain ambiguous loss
- Increase confidence to educate family-caregivers about the grief and grieving process
- Increase confidence in implementing emotion-focused coping strategies with a family-caregiver
- Increase confidence in implementing problem-solving focused coping strategies with family-caregivers
- Increase confidence in helping family-caregivers validate their emotions
- Increase occupational therapists perception that they are uniquely skilled to address psycho-emotional needs of family-caregivers

### Research Design

- One group pre- and post-test design to provide information about changes in knowledge following exposure to the independent variable, the two-hour seminar.
- The dependent variables include
  - Perceived confidence in ability to address the psycho-emotional needs of family-caregivers of an individual who sustained a TBI
  - Perceived ability to explain the concept of ambiguous loss to family-caregivers and that it is possible to grieve someone who is still living
  - Perceived ability to educate family-caregivers on emotion-focused and problem-solving focused coping strategies
  - Perceived ability to validate a family-caregiver's emotions
  - Perception that occupational therapists are uniquely skilled to address the psycho-emotional needs of family-caregivers or if other professions are more qualified.

### Participants

- EWU MOT students and OTs in the greater Spokane region

### Seminar Design

- The seminar was designed based on the themes that emerged from the literature review.
- Seminar content included: Ambiguous loss, validating emotions, grief and grieving, coping strategies, further resources, and a handout on basic TBI information.
- Discussion points throughout the seminar were incorporated using a case study.

## Questions

### Quantitative Questions

**Question 1:** I feel confident in my ability to address the psycho-emotional needs of an individual assuming the role of a family-caregiver(s).

**Question 2:** I feel confident in my ability to explain the concept of ambiguous loss to a family-caregiver(s).

**Question 3:** A family-caregiver(s) can grieve the loss of an individual who is still alive.

**Question 4:** I feel confident in my ability to educate a family-caregiver(s) on the process of grief and grieving.

**Question 5:** I feel confident in my ability to implement emotion-focused coping strategies with a family-caregiver(s).

**Question 6:** I feel confident in my ability to implement problem-solving focused coping strategies with a family-caregiver(s).

**Question 7:** I feel confident in my ability to help a family-caregiver(s) validate their own emotions.

**Question 8:** Occupational therapists are uniquely skilled at addressing the psycho-emotional needs of a family-caregiver(s).

**Question 9:** Other professions, like psychotherapists, are better equipped to provide psycho-emotional education to a family-caregiver(s) than occupational therapists.

### Qualitative Questions

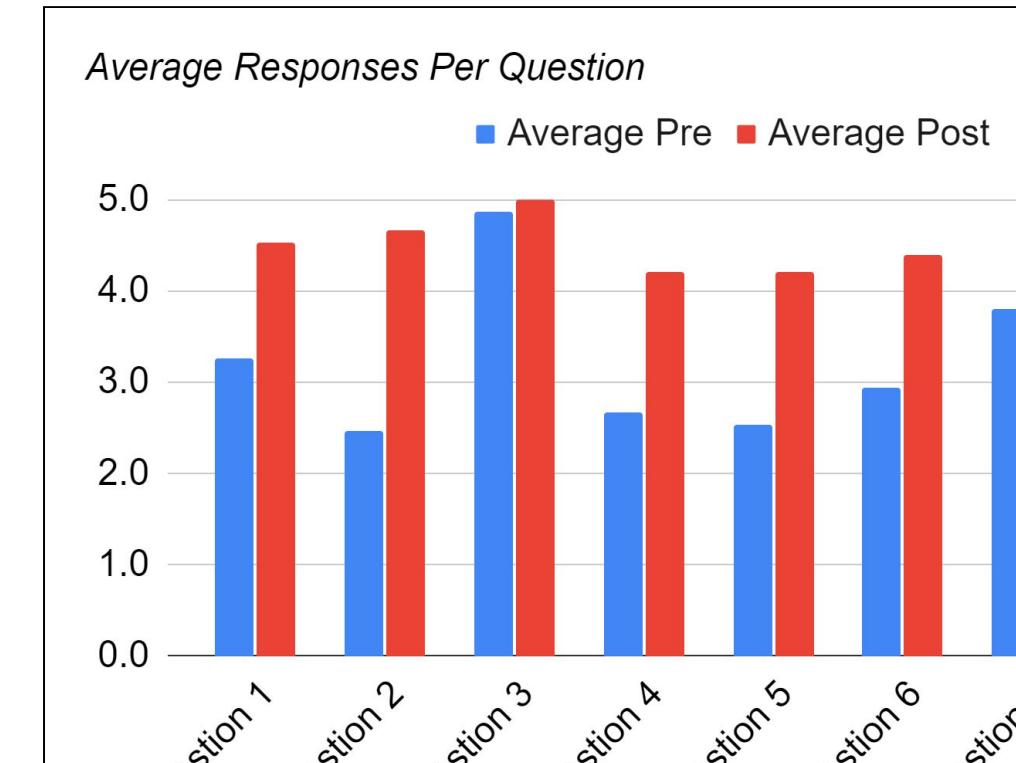
**Qual 1:** In what ways could occupational therapists be involved in supporting the psycho-emotional needs of family-caregiver(s) of individuals with a TBI?

**Qual 2:** After participating in this two hour seminar, please share three things you learned about ways that an occupational therapist could be involved in supporting the psycho-emotional needs of a family-caregiver(s).

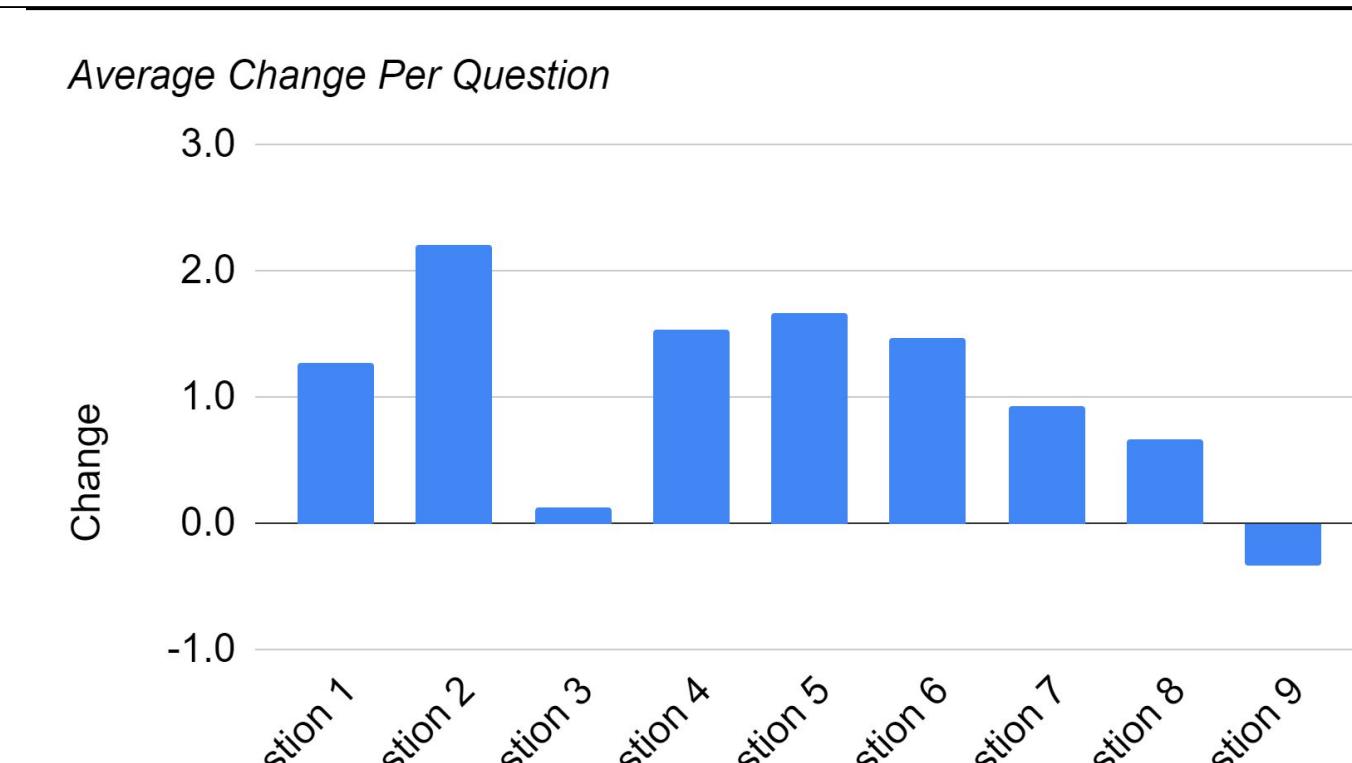
**Qual 3:** What topics could have been covered deeper in this two hour seminar that would have increased your knowledge?

**Qual 4:** Please describe one additional topic that could have been included in this seminar.

## Results



**Figure 1:** The graph represents the average response per question for both the pre (blue) and post (red) questionnaires.



**Figure 2:** The graph represents the average change in response per question.

### Statistically Significant Improvements Were Noted for 7/9 Quantitative Questions:

Questions 1, 2, 4, 5, 6, 7, and 8

### Thematic Analysis:

- Qual 1: Family training across the continuum of care, resources, and coping strategies.
- Qual 2: Validation, coping strategies, meaningful occupations, and ambiguous loss.
- Qual 3: Grief in the context of ambiguity, interventions and strategies to use, and what to do if the caregiver rejects their new role.
- Qual 4: Education, interventions, and adapting occupations.

## Conclusion

This research demonstrates that this 2-hour seminar did facilitate statistically significant changes in perceived knowledge amongst occupational therapy students and practitioners. It is theorized that by improving the knowledge base of OTs on the psycho-emotional needs of family-caregivers they will be better equipped to support this population. Future research should explore how OTs can successfully implement this type of psycho-emotional education with family-caregivers of an individual with a TBI and to evaluate its effectiveness with this population. Family-caregivers for individuals who sustained a TBI represent a large percentage of caregivers in the United States. As occupational therapists continue to serve family-caregivers, further research could enhance the quality of care provided to this population.

## Implications for Occupational Therapy

- The topics discussed in the this seminar are relevant to occupational therapy practitioners who provide caregiver education in their setting, specifically to family-caregivers of loved one's with a TBI.
- Improving caregiver competence and confidence with taking their loved one home is an important objective for OTs.
- When caregivers' psycho-emotional needs met they are less likely to experience burnout which leads to better patient outcomes.
- Explaining the concept of ambiguous loss in simple and understandable terms to family-caregivers can help them move through the grieving process.
- The OTPF-4 describes caregiving as a co-occupation because the relationship is reliant on both parties and involves integration of many occupations within the relationship (AOTA, 2020).
- The role of being a caregiver is so intertwined with the life of the recipient of care, it is relevant and important for the occupational therapy practitioner to consider the well-being of both partners throughout intervention and discharge planning.
- It is critical to utilize the most up-to-date evidence-based research to guide practitioners on the best ways to help family-caregivers with their psycho-emotional needs.