

CTE Hope Brain Injury Support Group

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BACKGROUND

More than 3.1 million children and adults in the U.S. live with a lifelong disability as a result of traumatic brain injury, and 6.4 million have a disability due to stroke (Brain Injury Alliance of Iowa, 2020). Individuals with brain injuries can struggle with physical, cognitive, behavioral, psychological and emotional problems (Bedard et al., 2003). A support group can be beneficial for an individual's activities of daily living as well as focusing on healthy interactions with others, reductions in isolation, the development of self-help and social skills, and reassurance and optimism about the future (Bedard et al., 2003).

Nearly 90% of caregivers of individuals with brain injuries report significant caregiver burden (Katz, Zafonte, & Zasler, 2013). When an individual experiences a brain injury a majority of the care taking is done by a family member who becomes the primary caregiver. The focus is often on the rehabilitation of the individual with the brain injury overshadowing the needs and psychosocial health of the caregiver (Qadeer, et al., 2017). Many caregivers share similar concerns and problem-solving strategies for caregiver tasks and find it helpful to discuss the emotional impact with others (Damianakis et al., 2016).

PROGRAM DETAILS

The purpose of the CTE Hope Brain Injury Support Group is to provide additional resources to brain injury survivors and their caregivers as well as create an environment that allows individuals to share their story and strategies that they have found to help improve their quality of life. Education will be integrated throughout the support group sessions on post-brain injury challenges and occupations that may be affected.

Based on survey responses, the support group will expect to take place once a month, in small in person groups of 4-6 people.

The group leader's role is to facilitate the discussion while maintaining a focus on the given topic for the month. The leader should give feedback and support while helping members of the group problem-solve.

FOCUSED QUESTION

What support do individuals with brain injuries and their caregivers need to improve their overall quality of life?

METHODS



CTE Hope
Research. Development. Support. Advocacy.

CTE Hope is a non-profit focused on providing education and awareness, and supports the research, diagnosis, management, and treatment necessary to protect individuals with brain injuries (CTE Hope, n.d.). Currently, individuals who visit the CTE Hope website with concerns, complete a patient contact form including information on past medical history, date of their first brain injury, current dietary habits, and resources they are seeking. The organization is then able to refer individuals to a functional neurologist in their state, as well as, provide additional resources.

The needs of the population served by the organization were assessed with a 10-question survey created based off of the knowledge and experience of the leaders within the organization. The survey was distributed via email to all individuals who have reached out to CTE Hope for resources.

The survey focused on:

- What type of support groups interest individuals with brain injuries and their caregivers
 - In person vs. video chat platform
- What occupations they are having the most difficulty with and/or would want more education on
- How often individuals would be willing to meet for a support group
 - Once a month, every other week, once every three months
- What secondary affects have individuals experienced from their brain injury
 - Anxiety and/or depression symptoms, job loss, homelessness, substance abuse, incarceration
- What emotions do individuals have difficulty managing
 - Rage, guilt, social isolation, mood swings, sadness, etc.

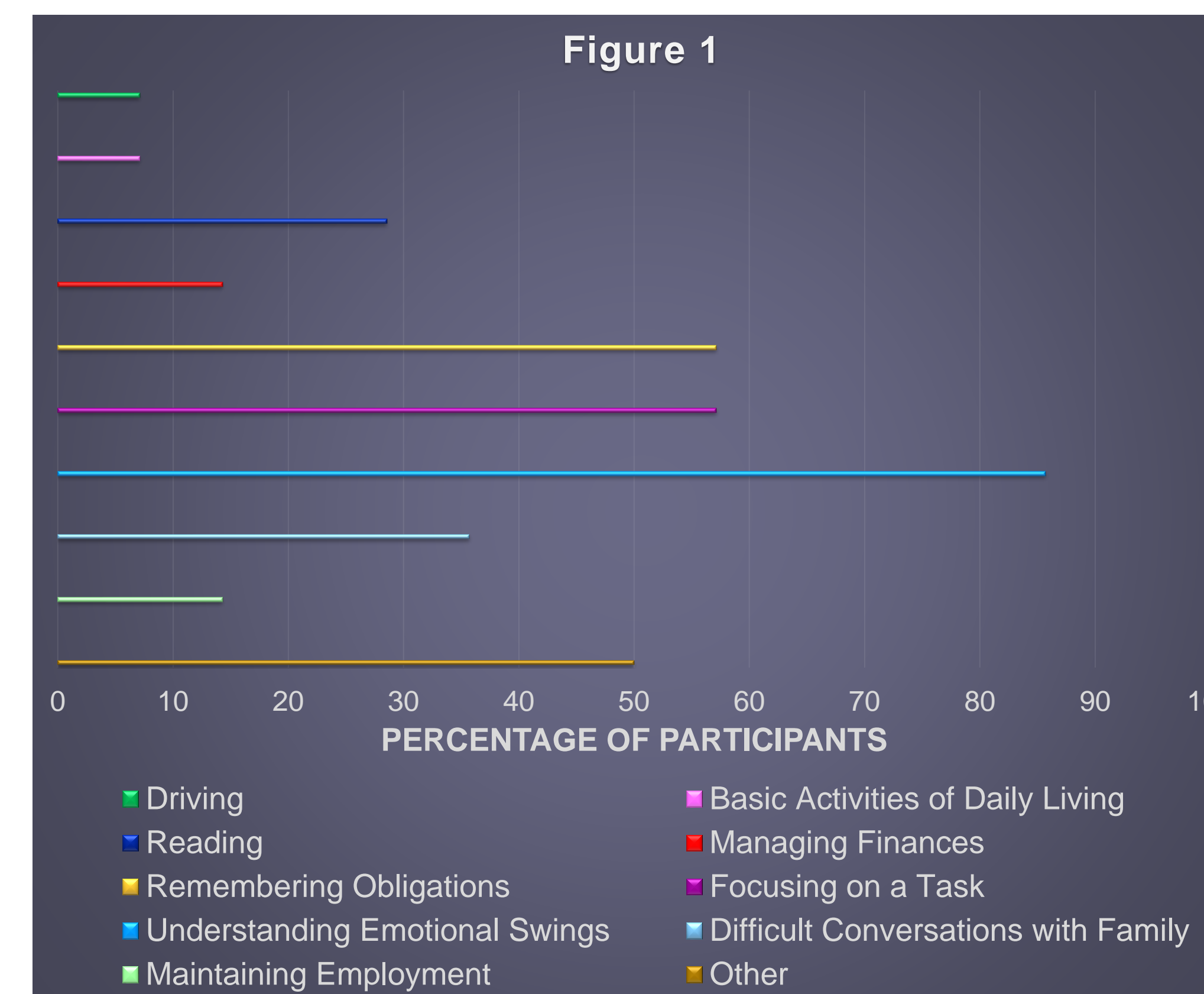
Additionally, personal information gathered from an individual who reached out to the organization during this time with concerns, was analyzed to encompass the subjective concerns of individuals with brain injuries in this survey.

Data gathered shows that, 100% of recipients of the survey indicated that they do not feel that they are receiving enough support managing their brain injury.

RESULTS

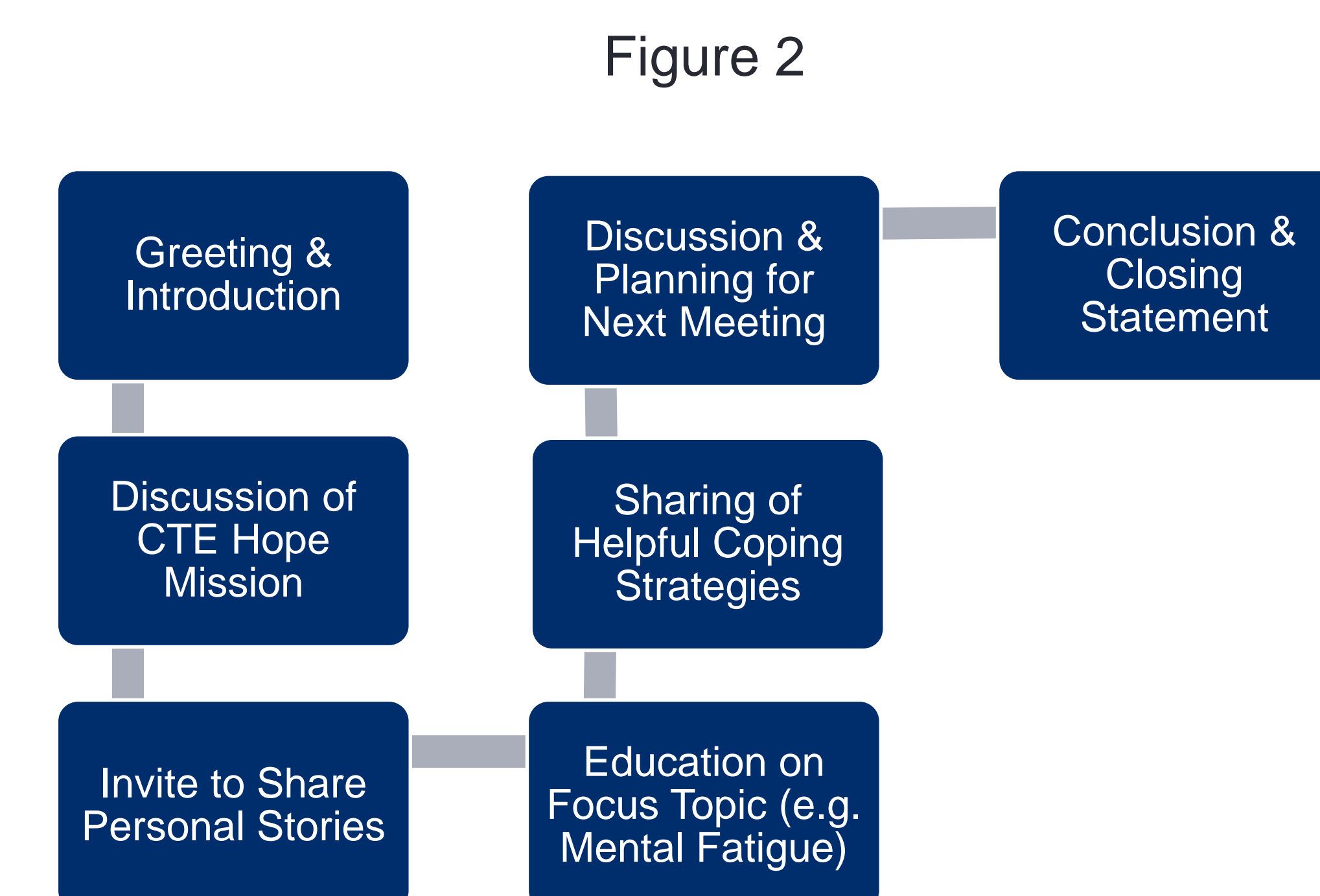
Results from the needs assessment suggest that participants would create a community of caregivers and survivors to support each other emotionally, that allows them to express their feelings, gain hope for the future and provide resources to one another.

Recipients of the survey were asked what activities they are having difficulty with to help determine the most appropriate discussion topics for the group as well as what educational resources to provide. See the survey results below in Figure 1.



Individuals that indicated 'other' reported chronic pain, providing emotional support, maintaining relationships, physical symptoms, brain flooding, and finding help that is covered by insurance.

The structure and design of the group meetings are unstructured, client-centered and modeled after a web-based support group for family caregivers of survivors with traumatic brain injury (Damianakis et al., 2016). Figure 2 shows an example of a meeting agenda.



BOTTOM LINE FOR OT

The care for individuals who have had brain injuries is complex and these individuals need to be included in the development of meaningful client centered goals.

Some individuals who have sustained several brain injuries have not received therapy services but have activities of daily living that are highly impacted by the affects of their brain injuries.

Many individuals do not feel they are receiving enough support with their brain injury and occupational therapists can be a great liaison to a variety of community resources for individuals and their caregivers.

Occupational therapists can provide compensatory strategies for activities that are most challenging for individuals in the support group. Occupational therapists also have the skill set to facilitate the group focusing on what is most important to the individuals and their caregivers.



<https://healthblog.ucsfhealth.org/brain-health/7-lessons-i-learned-as-a-levy-body-dementia-support-group-facilitator>

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