Health literacy for individuals with spinal cord injuries (SCIs) and traumatic brain injuries (TBIs) and their caregivers

Deja Motley, OTS; Mary H. Bowman, OTR/L

Department of Occupational Therapy | University of Alabama at Birmingham

Bethany Leonard, LMSW | Alabama Head Injury Foundation

Introduction

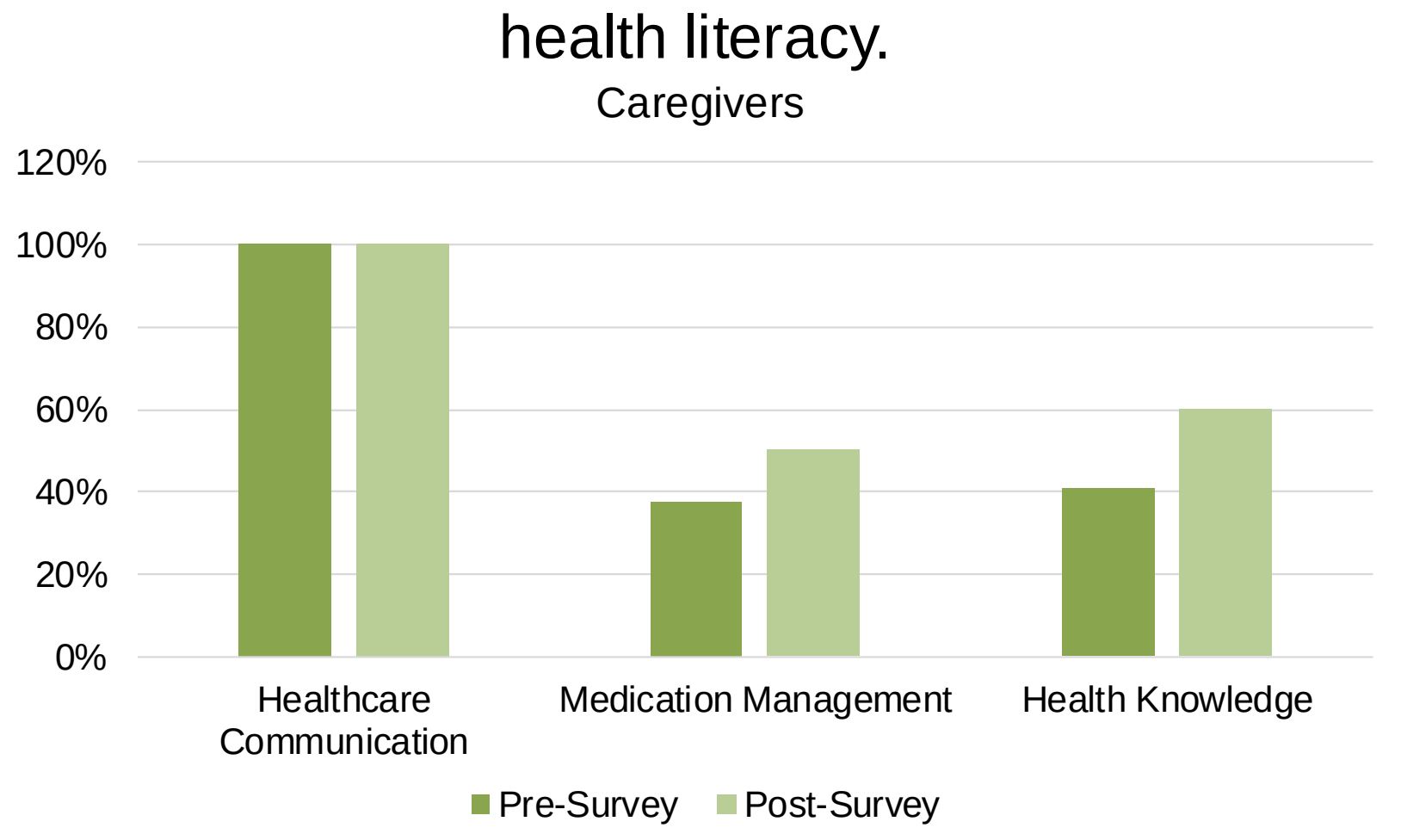
- Health Literacy is the ability to navigate and understand health services to make informed decisions for themselves and others (Centers for Disease Control and Prevention, 2020). It is integral to a person's ability to manage and maintain their health. Despite this, many Americans struggle with low health literacy.
- "9 out of 10 adults struggle with health literacy." (National Library of Medicine) This means 90% of Americans are more likely to make medication errors, struggle managing chronic illness, or skip preventative services.
- The scope of occupational therapy (OT) includes advocating for and educating clients and providing resources for practical patient education materials. According to the Occupational Therapy Practice Framework: Domain and Process-Fourth Edition, health management involves managing and maintaining health to improve or maintain health (2020).
- Occupational therapy practitioners have the capability to lead group and individual sessions to give clients the information accurately and help them as they learn to put the information to work.
- Despite health literacy being included in the OT framework, little scholarly research exists about the role of OT in this field.
- Research literature for health literacy details the current gaps, including the impact of low health literacy on patient outcomes, guidelines for appraising and modifying patient education materials, and the effectiveness of modified patient education materials (Attard et al., 2021).
- Previous research in health literacy shows that there is a lack of knowledge for much of the population with SCI, TBI, and their caregivers.
- The purpose of this project was to develop and implement a program that would help improve the health literacy of people with SCIs and TBIs and their caregivers.

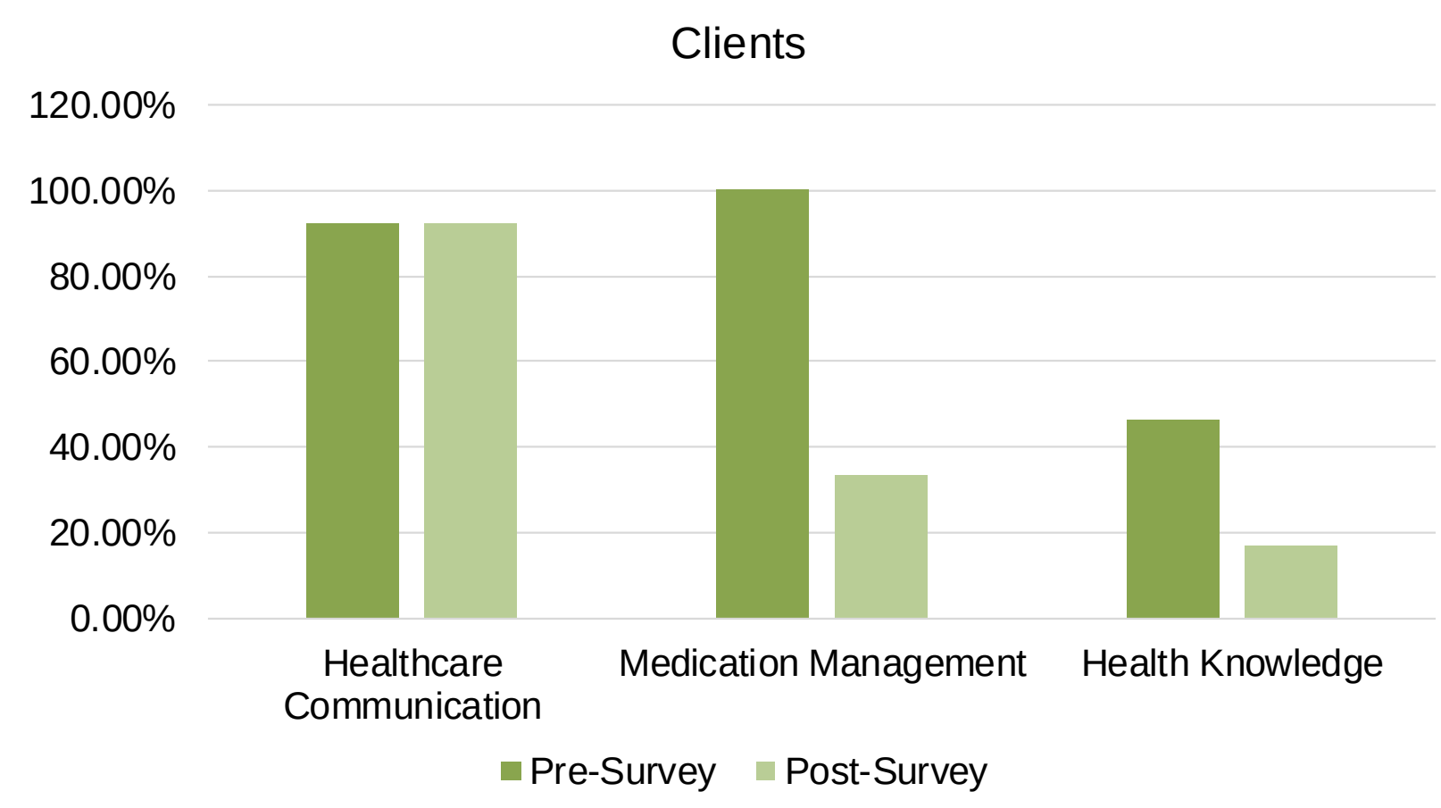
Methods

- This study consisted of a health literacy program delivered through the Alabama Head Injury Foundation (AHIF) with eight weekly sessions on a virtual meeting platform (Zoom) with participants that consisted of people with SCI and/or TBI and their caregivers.
- Each participant completed health literacy surveys by Qualtrics pre- and post-intervention.
- The survey collected simple demographic information from the participants, including age, gender, diagnoses, and client or caregiver status. The survey did not collect any personal or identifiable information.
- The next portion of the survey focused on the client's perceived efficacy of navigating their healthcare network, health management, and knowledge of available resources.
- The participants also had an opportunity to express any areas they had any concerns with.
- During the program, participants attended eight health literacy sessions using a virtual meeting platform (Zoom) where they were provided with health information with sessions addressing:
    - Medication Management
    - Local and National Resources
    - Health Knowledge
    - Health Record Keeping
    - Health Management
    - Doctor Visit Preparation
    - Burnout
    - Advocacy
- At the end of each session, there was a Q&A period to address any additional questions or information requested by the participants.
- Participants were provided with weekly PDFs on the information covered and a comprehensive packet of health literacy information at the end of the program.

Results

- Data was collected through pre- and post-intervention surveys during Qualtrics, including client and caregiver reports.
- Demographics:
    - Eight TBI or SCI clients and 68 caregivers were contacted from an AHIF member list.
    - From those contacted, three caregivers and two clients were enrolled and completed pre-surveys.
    - Two caregivers and one client completed the program, with one caregiver withdrawing in week 3 and one client withdrawing before the program began.
    - All participants were Caucasian, female, and >50 years old.
- Attendance:
    - Average attendance rate was 91% for caregivers and 100% for clients.
- Survey Results:
    - In the written feedback of the post-survey data, one participant reported that sessions had "definitely" helped them fill in the knowledge gaps related to their health literacy.





Discussion

- The purpose of this study was to improve participants' health literacy.
- The increase in caregiver literacy suggests that the information is helpful and can lead to positive changes for the participants.
- The client had a decrease in Medication Management and Health Knowledge. One possible reason for the decrease in the client's results might be increased awareness of gaps in their knowledge.
- Participants were given the opportunity throughout the study to request information pertaining to the upcoming topics every week. Common theme in the requests for more information focused around financial, accessibility, and health practice information/resources available to them.

Limitations:

- Recruitment:
    - Despite the large number of potential participants recruited, only 4 were enrolled to participate, with 3 completing the study. However, the participants had high attendance rates and gave positive feedback throughout the study.
- Time:
    - The short amount of time available during the OTD Capstone project proved challenging for recruitment and limited the ability for people to join. Particularly, after the recruitment period ended, two participants who expressed interest were unable to join. Similarly, time was a factor as change in health literacy may need more time to adequately assess in those participating in a program.
    - Since increasing health literacy is an ongoing process and the tasks that involve health management often do not occur daily or weekly, there was less opportunity for participants to use the information given to them during the study.

Discussion continued

- Low Response for Open-Ended Questions:
    - Limited specific open-ended feedback from study participants.
- Demographics:
    - The sample pool was limited with no males in either the caregiver or client group, and all participants were over the age of 50. Neither the clients nor caregivers who were involved in the study had new diagnoses of SCI or TBI since all had many years of lived experience from the onset of injury or since they began caregiving.

Implications for Future Research:

- It would be beneficial to include a qualitative portion to the study with participant interviews or a focus group to increase the specific feedback.
- A longer study period could allow participants the opportunity to practice information given during the program.

Conclusion

Despite the limitations of the study, the feedback from the participants suggests that continued research in this area of study will enhance caregiver and client confidence in their health literacy and ability to complete health management tasks. Further research in these areas will continue to enhance the understanding of the role of occupational therapy in health literacy and improve the health literacy of those receiving these beneficial services.

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Contact Information: dejagm@uab.edu

UAB SCHOOL OF HEALTH PROFESSIONS
The University of Alabama at Birmingham