

HHS Public Access

Author manuscript Brain Inj. Author manuscript; available in PMC 2021 November 29.

Published in final edited form as:

Brain Inj. 2020 May 11; 34(6): 697-707. doi:10.1080/02699052.2020.1752937.

Improving well-being after traumatic brain injury through volunteering: a randomized controlled trial

Lisa Payne^a, Lenore Hawley^a, Clare Morey^a, Jessica M. Ketchum^a, Angela Philippus^a, Mitch Sevigny^a, Cynthia Harrison-Felix^a, Ed Diener^{b,c}

^aResearch Department, Craig Hospital, Englewood, CO, USA

^bPsychology Department, University of Utah, Salt Lake City, UT, USA

^cPsychology Department University of Virginia, Charlottesville VA, USA

Abstract

Objective: To evaluate the efficacy of a novel intervention facilitating volunteer activity to improve well-being in individuals with traumatic brain injury (TBI).

Design: Randomized two-arm controlled trial, with a wait-list control condition (ClinicalTrials.gov NCT#01728350).

Setting: Community-based setting.

Participants: Seventy-four community-dwelling individuals at least 1-year post TBI, who had completed inpatient or outpatient TBI rehabilitation.

Interventions: A novel intervention, HOPE – Helping Others through Purpose and Engagement, involving orientation/training and a 3-month volunteer placement for the participant, along with training for community agencies regarding TBI.

Main outcome measure(s): Satisfaction With Life Scale (SWLS); Flourishing Scale (FS); Brief Symptom Inventory-18 (BSI-18); Scale of Positive and Negative Experience (SPANE); Purpose in Life subscale (one of six in the Ryff Scale of Psychological Well-Being – 54 item version).

Results: There were significantly greater improvements in life satisfaction (SWLS) and selfperceived success (FS) in the intervention group compared to the control group. There were no significant treatment effects on the additional secondary measures of well-being, although they trended in a positive direction.

Conclusions: This study supports our primary hypothesis that individuals who take part in a volunteer intervention will demonstrate greater psychological well-being in comparison to a control group.

Declaration of interest The authors have no conflicts of interest. Suppliers

CONTACT Lenore Hawley lhawley@craighospital.org Craig Hospital, Englewood, CO, 3425 S. Clarkson St., Research Department, Craig Hospital, Englewood, CO, USA.

Keywords

Traumatic brain injury; volunteering; life satisfaction; well-being

Introduction

Depression, anxiety, social isolation, and decline in productivity and life satisfaction are common sequelae of traumatic brain injury (TBI) (1–4). Life satisfaction, positive and negative emotions, social relationships, and purpose in life are all components of well-being (5–7). Meaningful productive activity is vital to developing life satisfaction and a sense of contribution to society, and often provides an avenue for social interaction (8–10). However, individuals with moderate to severe TBI often are unable to return to competitive employment, with return to work rates reported as low as 30% (11–13). Many individuals living with TBI spend their time alone in activities that are not productive for themselves or society (3). Psychological distress is common post-TBI, with estimates of anxiety disorders ranging from 11% to 70% and depressive disorders ranging from 25% to 42% (1,2). The combination of diminished productivity, social isolation, and psychological issues can make well-being elusive for individuals post-TBI. The long-term costs of impaired well-being post-TBI are realized through lost relationships, decreased productivity, and lowered self-esteem for the individual and family, as well as the financial costs of ongoing therapy and case management services (14–19).

Volunteer work has been found to have a positive effect on well-being in the general population (20–23). Volunteering offers an avenue for productivity, social involvement, and looking outside of oneself (21,23). Helping others has also been associated with higher levels of psychological health, happiness, life satisfaction, and self-esteem, as well as reduced stress and decreased depression, all components of well-being (21,23–25). In addition, volunteering has been shown to benefit working memory and processing in older adults (26). An important moderator of the positive effects of volunteering appears to be the level of social integration of the individual who is volunteering (21). Individuals with disabilities are usually regarded as recipients of volunteer work, rather than as volunteers. However, studies have shown that individuals with disabilities who provide volunteer services benefit from volunteering. For example, individuals with mental illness who served as volunteer peer counselors reported increased self-confidence and communication skills (27); individuals with multiple sclerosis providing volunteer peer support reported improved well-being (22); and individuals with SCI who identified themselves as volunteers reported increased quality of life, adjustment, and general health, along with fewer depressive symptoms and hospitalizations (28). In spite of these positive findings, Miller (29) reported that only 5.4% of all volunteers are individuals with disabilities.

The potential benefits of volunteer work appear particularly applicable to the needs of those with TBI, considering the difficulties they face regarding competitive employment, psychological adjustment, and social involvement, but there is minimal research about the effects of volunteering on well-being after TBI. One TBI study on fatigue reported an incidental finding that volunteering was positively associated with well-being, and suggested

more research should be done in this area (30). Volunteering after TBI appears to have the potential to provide a pathway to both increase productive activity and involvement in social interactions, and to enhance well-being for individuals with TBI.

Securing an appropriate volunteer placement requires planning, organization, initiation, and persistence, all cognitive functions that can be problematic for individuals with TBI (31). While those with TBI may benefit from volunteer activity, they may not be successful in their efforts to volunteer without a structured system to educate community agencies about TBI, and to assist people with TBI in initiating and following through on securing volunteer opportunities (32).

Yasuda (11), in a review of the literature related to return-to-work for individuals with TBI, has several recommendations for a successful return to work that could be applied to interventions developed for successful participation in other forms of productive activity, such as volunteering. These include: get to know the person; identify work opportunities that are a "good match" for the person; provide on-the-job supports and compensatory strategies; understand and manage behavior; and provide ongoing support, including a good relationship with the workplace.

There is consistent evidence that volunteering is positively associated with well-being; however, there has yet to be a randomized controlled trial (RCT) establishing an evidencebase for volunteering as an intervention to improve well-being post-TBI. If participation in volunteering by individuals with TBI leads to improvements in well-being and psychological health, then rehabilitation professionals should be educating patients about the benefits of volunteering, encouraging engagement in volunteer activities, and implementing programs to assist individuals post-TBI in successfully obtaining volunteer placement. Volunteering could lead to a reduced need and cost for long-term services, and allow individuals with TBI to provide a service to society.

A small unpublished study was completed by the authors to test the feasibility of conducting an efficacy study regarding volunteering as a method for improving well-being post-TBI. Individuals post-TBI were assessed on measures of well-being and then assisted in securing volunteer placements in the community. The feasibility study provided an opportunity to solidify details of the intervention, verify outcome measures, and offer evidence that the intervention was worthy of further study. Participants in the feasibility study were able to complete a 3-month volunteer intervention and showed improvement on all measures of well-being including significant improvement of life satisfaction and a marginally significant improvement in purpose in life. These encouraging results suggested the need for further research.

The purpose of this study was to evaluate the efficacy of a novel intervention facilitating volunteer activity to improve well-being in individuals with TBI. It was hypothesized that individuals who take part in a volunteer intervention would demonstrate greater improvements in well-being, life satisfaction, and emotional distress in comparison to a control group, both immediately following the 18-week intervention and through 3 and 6 months post-intervention.

Materials and methods

Participants

Seventy-four community-dwelling individuals at least 1-year post-TBI who met inclusion/ exclusion criteria in Table 1 (33).

Procedure

Following institutional review board approval, recruitment information was mailed to former patients with TBI who had graduated from our rehabilitation hospital; posted on the hospital website/social media; provided to local organizations serving people with TBI; and shared through public media. Individuals expressing interest were screened via telephone. Those meeting criteria came to the rehabilitation hospital to provide written informed consent and complete baseline assessment. Participants were randomized to treatment (n = 38) or control (n = 36) group with equal probability using computer-generated randomization.

Treatment group participants began the study intervention after baseline assessment. All participants were reassessed on outcome measures at 18, 30, and 42 weeks postbaseline testing. After the 42-week assessment, control group participants were offered the opportunity to complete the study intervention, although no data were collected after this point. See timeline in Figure 1.

Study personnel and participants were blind to treatment assignment until enrollment and baseline assessment were completed. After baseline assessment, participants were assigned to treatment or control group using a computer-generated randomization scheme with equal probability. The study coordinator then notified participants of the group assignment. Throughout the study, staff administering assessments were blind to group assignment. Participants were instructed not to reveal group assignments to assessment administrators.

All participants, treatment and control, received 150 USD to compensate for transportation costs during the course of the study. This compensation was provided in three 50 USD payments during month 2, month 3, and month 4 of the study. For those in the treatment group, these payments coincided with each of the 3 months they were volunteering.

Intervention

The HOPE – *H*elping *O*thers through *P*urpose and *E*ngagement intervention was developed as part of the current research project. The intervention is based on the study investigators' experience and understanding of the challenges faced by individuals with TBI, as well as theories of psychological well-being, including social learning theory, positive psychology, behavior theory, and existential psychology. The intervention lasted 18 weeks following baseline; 6 weeks for HOPE Orientation and volunteer placement, followed by 12 weeks of volunteering. The intervention involved collaboration with a community-based volunteer placement agency with expertise in connecting volunteers with agencies needing volunteer interests, orientation/training, placement assistance, 3-month volunteer placement, and problem-solving and support. The study Principle Investigators

(PIs), who developed the HOPE program, provided training/orientation for the Volunteer Placement Coordinator (VPC) at the volunteer placement agency, and for agencies interested in accepting participants as volunteers. Training/orientation included information about TBI and strategies for supervising individuals with TBI in a volunteer setting. Prior to the HOPE program, the volunteer agency and community placement agencies were not aware of the specific adaptations necessary for a successful volunteer experience for individuals with TBI. Individuals with TBI wishing to volunteer without a supportive intervention such as HOPE do not have access to TBI specific training, suggestions, and support.

Study PIs and the VPC met with each participant in the treatment arm to assess interests and provided an orientation regarding volunteering after TBI. Orientation covered challenges that might be encountered when volunteering after TBI, and strategies to overcome these challenges, enhance self-confidence, and improve skills for the volunteer placement.

Once a volunteer placement was identified, the VPC scheduled and attended an initial interview/orientation at the volunteer placement with the participant. This allowed the participant and agency to ask questions, understand assigned tasks, and explain modifications that might be needed with the support of the VPC. Participants were asked to volunteer a minimum of 3 h weekly during the 3-month intervention phase. The VPC contacted the agency during the first 2 weeks of placement to answer questions and confirm participants were volunteering as scheduled. Study PIs contacted participants after 2 weeks of volunteering to assist in problem-solving and necessary additional strategies and support.

8The VPC made monthly contact with the agency to collect volunteer hours and answer questions. Volunteer agencies could request assistance from VPC and study PIs to resolve problems or develop compensatory strategies for working with the participant. Agencies where volunteers were placed included food banks, museums, programs for the elderly, community gardens, and nonprofit advocacy organizations.

Two HOPE Handbooks were developed and provided to treatment participants and volunteer agencies. These handbooks provided a reference for the information covered in the HOPE orientation sessions (Figure 2).

Measures

Demographic, cognitive, and injury characteristics

Demographic information (age, gender, marital status, race/ethnicity, education, income, living situation, pre-injury employment) and cause of TBI were collected at baseline. In addition, a baseline cognitive screen that included WAIS-III Processing Speed Index (34), Trail Making Test (35), Rey Auditory Verbal Learning Test (36), and the Medical Symptom Validity Test (37) was administered to characterize the cognitive status of participants. Baseline demographic and cognitive screening results are detailed in Payne *et al.* (33).

Primary outcome measure

<u>The Satisfaction with Life Scale (SWLS).</u>: The Satisfaction with Life Scale (SWLS) is a global measure of life satisfaction which has been validated in persons with TBI (38). Total

Secondary outcome measures

The Flourishing Scale (FS).: The Flourishing Scale (FS) is a global measure of well-being (i.e., self-esteem, purpose, optimism). Total scores on this 8-item Likert scale range from 8 to 56 with greater scores indicative of greater well-being (39).

The Brief Symptom Inventory-18 (BSI-18).: The Brief Symptom Inventory-18 (BSI-18) is a widely used measure of psychological distress with demonstrated validity and reliability in the populations of people with TBI (41). The 18 items on this measure are each rated on a Likert scale and provide an overall score (Global Severity Index or GSI) of psychological distress, as well as sub-scores in areas of somatization, depression, and anxiety. T-scores of 63 or higher are indicative of distress (40).

Scale of Positive and Negative Experience (SPANE).: Scale of Positive and Negative Experience (SPANE) is a 12-item questionnaire that evaluates how often a person experiences 6 positive and 6 negative feelings using a Likert scale for each item. Total negative feelings score (range 6 to 30) is subtracted from total positive feelings score (range 6 to 30) to obtain an overall balance score (SPANE-B). SPANE-B scores range from -24 to 24 with higher scores indicating higher affect balance (39).

The purpose in life subscale is one of the six subscales in the Ryff scale of psychological well-being – 54 item version.: This subscale is a nine-item measure which assesses a person's goal orientation and conviction that life holds meaning. Responses are on a Likert scale with a total score ranging from 9 to 54. Higher scores on this scale are indicative of greater well-being and sense of purpose (6).

Additional data collection: At 30-week and 42-week assessment points, participants in the treatment group were asked if they had continued volunteering at their volunteer placement. The study requirement was that participants volunteer for 3 months, but we did not require that they stop volunteering at the end of the 3 months. We were interested in how many people would stay in their volunteer placement beyond the required 3 months.

Power and sample size calculations

An *a priori* sample size estimation/power analysis (using PASS 14^a) was conducted based on detecting a moderate treatment by time effect size of 0.5 with 80% power in a two-arm design with four repeated measurements of the SWLS at a 5% level of significance. Based on this analysis, it was determined that a minimum of 25 participants per treatment group (50 total) would be needed for this study. A total of 74 were recruited to account for attrition/drop-out.

^aPASS 14 Power Analysis and Sample Size Software [computer program]. Kaysville, Utah, USA: NCSS, LLC; 2015.

Brain Inj. Author manuscript; available in PMC 2021 November 29.

Statistical analysis

All statistical analyses were conducted using SAS v.9.4^b. Demographic and injury characteristics were summarized using means/standard deviations (SDs) or medians/ interquartile ranges (IQRs) for continuous variables and frequency counts/percentages for nominal variables. These characteristics were compared between the two groups using t-tests, Wilcoxon rank-sum tests, and chi-square tests to assess for potential baseline differences after randomization when sample size and distributional assumptions were met.

Data were analyzed as intent-to-treat, using all available data from all participants according to randomized treatment assignment. The primary and secondary outcomes were each analyzed using a repeated-measures linear mixed-effects model assuming a compound symmetry correlation structure among the four repeated measures. These models included fixed effects for treatment group and time, and the interaction between treatment group and time, as well as effects for age, years since injury, gender, race, marital status, pre-injury employment status, level of education, and baseline BSI-GSI T-scores. Baseline BSI-GSI T-scores were included as a covariate to account for baseline imbalances between the groups after randomization and due to the expected association with the outcomes of interest. An omnibus test of the treatment \times time interaction effect was first conducted to determine if the two treatment groups exhibited significantly different changes in the outcome variables over the four time points (baseline (0), 18, 30, and 42 weeks). If the omnibus test of the interaction was significant ($\alpha = 0.05$), then post hoc analyses were conducted to determine how the groups differed specifically in their patterns of change from baseline. Differences in the changes from baseline to immediately post-intervention and through follow-up were compared between groups using a Bonferroni adjustment of $\alpha = 0.05/3 = 0.0167$ to control for multiple comparisons. Effect sizes were estimated to be the mean estimate (either the within-group change or the between-group difference in changes) divided by square root of the model-based variance for each outcome. This denominator is an approximation of the pooled standard deviation of the outcome variable, irrespective of group and time. The sensitivity of these results was compared across three other modeling scenarios including (a) unadjusted for covariates, (b) using the last observation carried forward for participants with missing data, and (c) using the subsample of 58 participants (26 treatments and 32 controls) with complete outcome data at all four time points.

Results

The consort diagram in Figure 3 summarizes the sample flow chart for this study. A total of 74 participants were enrolled and completed baseline assessments. Thirty-eight participants were randomized to treatment and 36 participants were randomized to control. Demographic and injury characteristics are summarized by treatment group in Table 2. Groups did not differ significantly on any of these characteristics (all p's > 0.36). Sample size assumptions (expected frequencies 5) were not met for statistical comparisons between the treatment groups on household income, residence, living situation, or cause of injury; however, no notable differences in these distributions were observed. Cognitive, psychological, and well-

^bSAS System Version 9.4 [computer program]. Cary, NC: SAS Institute Inc.; 2002–2012.

being characteristics at baseline are summarized by treatment group in Supplementary Table S1. Groups were similar at baseline on all well-being outcomes with the exception of BSI. The control group had significantly lower BSI Anxiety T-scores (54.6 vs. 61.3, p = 0.0230) and marginally lower BSI Depression (57.6 vs. 61.8, p = 0.0947) and BSI-GSI T-scores (59.3 vs. 63.3, p = 0.0907) as compared to the treatment group.

The unadjusted means and SDs for each well-being outcome are summarized over time and by the group in Supplementary Table S2. The estimated mean outcomes from the repeated-measures models, adjusted for covariates, are plotted in Figure 4. The estimated change in outcome from baseline to each endpoint (18, 30, and 42 weeks) within each group and the difference in changes between groups are summarized for each outcome, along with associated standard errors, 95% confidence intervals, and estimated effect sizes, in Table 3.

Satisfaction with life

There was a significant difference in the changes in mean SWLS over time between the two groups (treatment \times time interaction p = 0.0157), after adjusting for age, years since injury, gender, race, marital status, pre-injury employment status, education level, and BSI-GSI T-score at baseline. The estimated model-based variance in SWLS was 44.52 and the correlation among the repeated measures was estimated to be 0.68. The treatment group showed *nominally* (non-significant) greater increases in mean SWLS than the control group from baseline to 18 weeks (difference in increases = 2.46, p = 0.0632) and significantly greater increases from baseline to 30 weeks (difference in increases = 4.02, p = 0.0035) and from baseline to 42 weeks (difference in increases = 3.53, p = 0.0096). Over the 42-week study period, the treatment group increased 5.5 units on the SWLS compared to a 1.9 unit increase in the control group. Effect sizes within the treatment group were 0.58 at 18 weeks, 0.87 at 30 weeks, and 0.82 at 42 weeks, all considered to be moderate (0.5) to large (0.8). Effect sizes within the control group were small, ranging from 0.21 to 0.29. Between-group effect sizes increased from 0.37 at 18 weeks to 0.60 at 30 weeks and 0.53 at 42 weeks. Covariate effects in the adjusted model were not significant for age, year since injury, gender, race, marital status, employment, or education (all p's > 0.30). However, there was a significant negative relationship between baseline BSI-GSI scores and SWLS scores (slope = -0.21, p = 0.0063). The results from this adjusted model using all available data from all cases were similar compared to the results from the model not adjusting for covariates and for the subsample with complete data. Results using the last observation carried forward were not significant at 18, 30, or 40 weeks and estimated differences were smaller, primarily due to smaller estimated changes within the treatment group.

Self-perceived success

There was a significant difference in the changes in mean FS over time between the two groups (treatment × time interaction p = 0.0372), after adjusting for baseline covariates. The estimated variance in FS was 59.84 and the correlation among the repeated measures was estimated to be 0.56. The treatment group showed *nominally* greater increases in mean FS than the control group from baseline to 18 weeks (difference in increases = 1.66, p = 0.3640) and from baseline to 30 weeks (difference in increases = 2.81, p = 0.1349), and *significantly* greater increases from baseline to 42 weeks (difference in increases = 5.35, p = 0.0045).

The treatment group increased 7.4 units on average over the 42-week study period and the control group increased 2.1 units. Effect sizes within the treatment group were 0.40 at 18 weeks, 0.66 at 30 weeks, and 0.91 at 42 weeks, all considered medium to large. Effect sizes within the control group were small and ranged from 0.20 to 0.31. Between-group effect

weeks, 0.06 at 50 weeks, and 0.91 at 42 weeks, an considered medium to large. Effect sizes within the control group were small and ranged from 0.20 to 0.31. Between-group effect sizes increased from 0.20 at 18 weeks to 0.34 at 30 weeks and 0.66 at 42 weeks. Covariate effects in the adjusted model were not significant for age, year since injury, gender, race, marital status, employment, or education (all *p*'s > 0.24). However, there was a significant negative relationship between baseline BSI-GSI scores and FS scores (slope = -0.36, *p* < 0.0001). The results from this adjusted model using all available data from all cases were similar compared to the results from the model not adjusting for covariates and for the subsample with complete data. Results using the last observation carried forward were not significant at 18, 30, or 40 weeks and estimated differences were smaller, primarily due to smaller estimated changes within the treatment group.

Additional secondary outcomes

There were no significant differences in the changes in mean outcome over time between groups for BSI-GSI (p = 0.2120), SPANE Balance (p = 0.2865), or Ryff Purpose in Life (p = 0.6288), after adjusting for baseline covariates.

Additional data

Treatment participants were asked to volunteer for a minimum of 3 h per week. Of the 38 treatment participants, 15 (40%) volunteered at least 3 h per week for at least 1 month and 10 did so all 3 months (26%). Participants in the treatment arm had the option to continue volunteering after the 12-week volunteer period. At 30-week follow-up, 42% (11/26) of participants in the treatment arm reported continuing to volunteer. This decreased to 32% (8/25) at 42-week follow-up.

Discussion

This study evaluated the efficacy of an intervention facilitating volunteering in the community as a means to improve well-being in individuals with TBI. Results support our hypothesis that individuals who take part in a volunteer intervention will demonstrate greater improvements in psychological well-being compared to a control group. Satisfaction with life and self-perceived success improved over time. Not all secondary measures of well-being were found to have significant treatment effects, although they trended in a positive direction.

Meaningful, productive activity is important to leading a satisfying life, yet the majority of individuals with chronic moderate to severe TBI do not return to competitive employment. Volunteering is a viable alternative for individuals with TBI who are unable to return to paid employment and are looking for meaning in life, social connection, and life satisfaction. Volunteering may be a cost-effective alternative to other ongoing psychological interventions.

Although individuals with TBI may be interested in volunteering, they often do not do so on their own. This study suggests that a structured intervention can facilitate the process of

volunteering for this population, addressing areas such as initiation, organization, and social skills. The HOPE intervention provides a link between individuals with TBI interested in volunteering and volunteer agencies seeking volunteers.

The results of this study are notable, given that participants scored severely low on SWLS at baseline. Statistically significantly greater improvements in SWLS from baseline were exhibited by the treatment group than the control group at both 30and 42-week follow-up. This could indicate that the desire to engage in meaningful activity was motivating, and engaging in that activity allowed for a sustained sense of life satisfaction. The HOPE intervention involves collaboration with community agencies, so that the individual can continue to flourish in the volunteer setting without therapeutic intervention. Training community partners so that they feel empowered to support individuals with TBI without continued therapeutic assistance allow for long-term success in the community.

Although treatment participants were asked to volunteer a minimum of 3 h per week, not all met that time requirement. However, the sample still made improvements in well-being. It would appear that the act of volunteering, rather than the amount of time spent, affects well-being and more research is needed to clarify the effect of time spent volunteering. Treatment participants continued to volunteer after the treatment period ended. This is notable since they were no longer being asked to volunteer beyond the 18-week study period.

The majority of participants were female. This finding is unusual as 1.4 times as many TBIs occur among males as among females (42) and the majority of participants in previous studies at this facility have been male. This higher number could be due to the fact that in general women are more motivated than men to volunteer (43).

Study limitations

In the feasibility study, transportation costs were found to be a significant barrier to volunteering. To alleviate this barrier, participants received 50 USD per month over the 3-month treatment period to assist with travel costs to and from the volunteer placement. To mitigate the effects of this payment, control participants also received these funds at the same time points. Treatment participants were volunteering their time and efforts, even though they were not bearing the cost of transportation. Although the control group was not offered the intervention until after all assessments were completed, the anticipation of this opportunity may have elevated their well-being on several measures toward the end of the study even though they had not yet volunteered. The mixed-effects model used all data available; however, 16 participants did not have data at all four time points. This may have introduced some bias into the estimates, particularly at baseline; however, all available data from these participants were included per intent-to-treat protocol.

Conclusions

This study provides evidence that volunteering leads to improvements in well-being after TBI. Engaging in volunteer activity positively impacts satisfaction with life as well as the perception of life success. Volunteering allows individuals with TBI who are not able to work competitively to be productive contributing members of society. The

authors recommend collaborating with community agencies to assist and facilitate volunteer placement for individuals living with TBI in the community, with the end goal of improving psychological well-being.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The contents of this manuscript were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0034). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this manuscript do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government. NCT#: 01728350

The authors thank Kristy Judd and her staff at Metro Volunteers (now Spark the Change Colorado) for their vital participation in this project; as well as Richard Owens for his thoughtful insight and assistance.

Funding

This work was supported by the National Institute on Disability, Independent Living, and Rehabilitation Research [90DP0034].

References

- Kreutzer JS, Seel RT, Gourley E. The prevalence and symptom rates of depression after traumatic brain injury: a comprehensive examination. Brain Inj. 2001;15(7):563–76. doi:10.1080/02699050010009108. [PubMed: 11429086]
- 2. Rao V, Lyketsos C. Neuropsychiatric sequelae of traumatic brain injury. Psychosomatics. 2000;41(2):95–103. doi:10.1176/appi.psy.41.2.95. [PubMed: 10749946]
- Winkler D, Unsworth C, Sloan S. Time use following a severe traumatic brain injury. J Occup Sci. 2005;12(2):69–81. doi:10.1080/14427591.2005.9686550.
- Lezak M. Living with the characterologically altered brain injured patient. J Clin Psychiatry. 1978;39:592–98. [PubMed: 681289]
- 5. Diener E, Emmons R, Larsen J, Griffin S. The satisfaction with life scale. J Pers Assess. 1985;49:71–75. doi:10.1207/s15327752jpa4901_13. [PubMed: 16367493]
- Ryff C. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. J Pers Soc Psychol. 1989;57 (6):1069–81. doi:10.1037/0022-3514.57.6.1069.
- 7. Kahneman D. Thinking fast and slow. New York: Farrar, Straus and Giroux; 2011.
- 8. Rice R, Near J, Hunt R. The job-satisfaction/life-satisfaction relationship: a review of empirical research. Basic Appl Soc Psych. 1980;1(1):37–64. doi:10.1207/s15324834basp0101_4.
- 9. Johansson U, Bernspang B. Life satisfaction related to work re-entry after brain injury: a longitudinal study. Brain Inj. 2003;17(11):991–1002. doi:10.1080/0269905031000110508. [PubMed: 14514450]
- O'Neill J, Hibbard MR, Brown M, Jaffe M, Sliwinski M, Vandergoot D, Weiss, MJ. The effect of employment on quality of life and community integration after traumatic brain injury. J Head Trauma Rehabil. 1998;13(4):68–79. doi:10.1097/00001199-199808000-00007. [PubMed: 9651241]
- Yasuda S, Wehman P, Targett P, Cifu D, West M. Return to work for persons with traumatic brain injury. Am J Phys Med Rehabil. 2001;80(11):852–64. doi:10.1097/00002060-200111000-00011. [PubMed: 11805460]
- Ponsford JL, Olver JH, Curran C, Ng K. Prediction of employment status 2 years after traumatic brain injury. Brain Inj. 1995;9 (1):11–20. doi:10.3109/02699059509004566. [PubMed: 7874091]

- Stambrook M, Moore AD, Peters LC, Deviaene C, Hawryluk G. Effects of mild, moderate, and severe closed head injury on long-term vocational status. Brain Inj. 1990;4(2):183–90. doi:10.3109/02699059009026164. [PubMed: 2331548]
- Ashman T, Cantor JB, Tsaousides T, Spielman L, Gordon W. Comparison of cognitive behavioral therapy and supportive psychotherapy for the treatment of depression following traumatic brain injury: a randomized controlled trial. J Head Trauma Rehabil. 2014;29(6):467–78. doi:10.1097/ HTR.0000000000000098. [PubMed: 25370439]
- 15. Cullen B, Pownall J, Cummings J, Baylan S, Broomfield N, Haig C, Kersel D, Murray H, Evans JJ. Positive PsychoTherapy in ABI Rehab (PoPsTAR): A pilot randomised controlled trial. Neuropsychol Rehabil. 2018;28(1):17–33. doi:10.1080/09602011.2015.1131722. [PubMed: 26726854]
- D'Antonio E, Tsaousides T, Spielman L, Gordon W. Depression and traumatic brain injury: symptom profiles of patients treated with cognitive-behavioral therapy or supportive psychotherapy. Neuropsychiatry. 2013;3(6):601. doi:10.2217/npy.13.75.
- Vangel SJ Jr., Rapport LJ, Hanks RA, Black KL. Long-term medical care utilization and costs among traumatic brain injury survivors. Am J Phys Med Rehabil. 2005;84(3):153–60. doi:10.1097/01.PHM.0000154896.55045.E7. [PubMed: 15725788]
- Rockhill CM, Jaffe K, Zhou C, Fan MY, Katon W, Fann JR. Health care costs associated with traumatic brain injury and psychiatric illness in adults. J Neurotrauma. 2012;29(6):1038–46. doi:10.1089/neu.2010.1562. [PubMed: 22142264]
- Kayani NA, Homan S, Yun S, Zhu BP. Health and economic burden of traumatic brain injury: Missouri, 2001–2005. Public Health Rep. 2009;124(4):551–60. doi:10.1177/003335490912400412. [PubMed: 19618792]
- Musick MA, Wilson J. Volunteering and depression: the role of psychological and social resources in different age groups. Soc Sci Med. 2003;56(2):259–69. doi:10.1016/S0277-9536(02)00025-4. [PubMed: 12473312]
- Piliavin JA, Siegl E. Health benefits of volunteering in the Wisconsin longitudinal study. J Health Soc Behav. 2007;48 (4):450–64. doi:10.1177/002214650704800408. [PubMed: 18198690]
- Schwartz CE, Sendor M. Helping others helps oneself: response shift effects in peer support. Soc Sci Med. 1999;48(11):1563–75. doi:10.1016/S0277-9536(99)00049-0. [PubMed: 10400257]
- 23. Thoits PA, Hewitt LN. Volunteer work and well-being. J Health Soc Behav. 2001;42(2):115–31. doi:10.2307/3090173. [PubMed: 11467248]
- 24. Post SG. Altuism, happiness, and health: it's good to be good. Int J Behav Med. 2005;12(2):66–77. doi:10.1207/s15327558ijbm1202_4. [PubMed: 15901215]
- Schwartz C, Meisenhelder JB, Ma Y, Reed G. Altruistic social interest behaviors are associated with better mental health. Psychosom Med. 2003;65(5):778–85. doi:10.1097/01.PSY.0000079378.39062.D4. [PubMed: 14508020]
- Proulx CM, Curl AL, Ermer AE. Longitudinal associations between formal volunteering and cognitive functioning. J Gerontol B Psychol Sci Soc Sci. 2018;73(3):522–31. doi:10.1093/geronb/ gbx110. [PubMed: 28958028]
- 27. Mowbray CT, Moxley DP, Thrasher S, Bybee D, McCrohan N, Harris S, Clover G. Consumers as community support providers: issues created by role intervention. Community Ment Health J. 1996;32:47–67. [PubMed: 8635317]
- Yuen H, Burik J, Krause J. Physical and psychosocial well-being among adults with spinal cord injury: the role of volunteer activities. Top Spinal Cord Inj Rehabil. 2004;9(4):19–25. doi:10.1310/ CKWU-XNMC-C6AA-P2VM.
- 29. Miller KD, Schleien S, Rider C, Hall C, Roche M, Worsley J. Inclusive volunteering: benefits to participants and the community. Ther Recreation J. 2002;36:247–59.
- Ouellet MC, Morin CM, Lavoie A. Volunteer work and psychological health following traumatic brain injury. J Head Trauma Rehabil. 2009;24(4):262–71. doi:10.1097/HTR.0b013e3181a68b73. [PubMed: 19625865]
- Lezak MD, Howieson DB, Loring DL, editors. Neuropsychological assessment. 4th ed. New York, NY: Oxford University Press; 2004.

- 32. Lindsay S. A scoping review of the experiences, benefits, and challenges involved in volunteer work among youth and young adults with a disability. Disabil Rehabil. 2016;38(16):1533–46. doi:10.3109/09638288.2015.1107634. [PubMed: 26678410]
- 33. Payne L, Hawley L, Ketchum JM, Philippus A, Eagye CB, Morey C, Gerber D, Harrison-Felix C, Diener E. Psychological well-being in individuals living in the community with traumatic brain injury. Brain Inj. 2018;32(8):980–85. doi:10.1080/02699052.2018.1468573. [PubMed: 29708442]
- 34. The Psychological Corporation. WAIS-III-WMS-III technical manual. San Antonio, TX; 1997.
- 35. Reitan RM. Trail Making Test: Manual for administration and scoring. Tuscon, AZ: Reitan Neuropsychological Laboratory; 1986.
- 36. Schmidt M. Rey auditory verbal learning test: a handbook. Los Angeles, CA: Western Psychological Services; 1996.
- 37. Green P. Medical Symptom Validity Test for windows: user's manual and program. Edmonton, Canada: Green's Publishing; 2005.
- Corrigan JD, Kolakowsky-Hayner S, Wright J, Bellon K, Carufel P. The satisfaction with life scale. J Head Trauma Rehabil. 2013;28(6):489–91. doi:10.1097/HTR.0000000000000004. [PubMed: 24189288]
- Diener E, Wirtz D, Tov W, Kim-Prieto C, CHoi D, Oishi S, Biswas-Diener R. New well-being measures: short scales to assess flourishing and positive and negative feelings. Soc Indic Res. 2010;97:143–56.
- 40. Derogatis L. Brief symptom inventory 18. Minneapolis: NCS Pearson, Inc.; 2001.
- Meachen S, Hanks RA, Millis S, Rapport LJ. The reliability and validity of the brief symptom inventory-18 in persons with traumatic brain injury. Arch Phys Med Rehabil. 2008;89(5):958–65. doi:10.1016/j.apmr.2007.12.028. [PubMed: 18452746]
- 42. Faul M, Xu L, Wald MM, Coronado VG. Traumatic brain injury in the United States: emergency department visits, hospitalizations and deaths 2002–2006. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.
- 43. United States Department of Labor. Volunteering in the United States, 2015. Bureau of Labor Statistics, Statistics BoL; 2016. Contract No.: USDL-16–0363.

Payne et al.

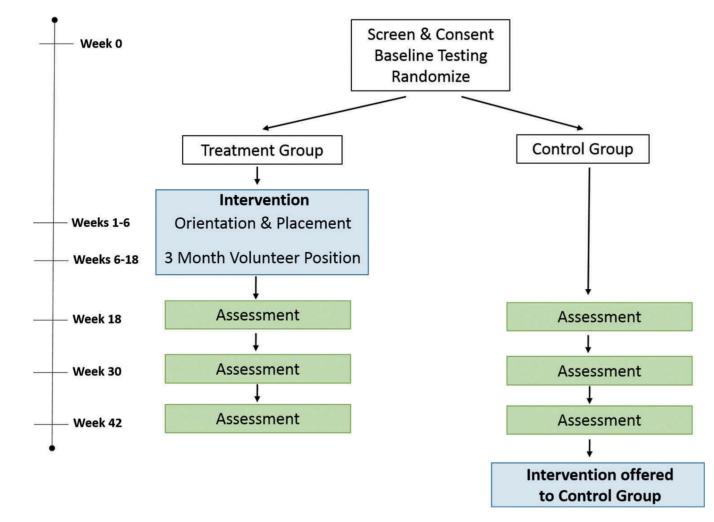


Figure 1. Study timeline.

Participant I	Handbook
---------------	----------

HOPE Helping Others <u>Through</u> F Engagement	Purpose &
	ndbook for Volunteers with TBI
Craig Hospital	
Volunteer Agency Handb	oook
HOPE	Conte
Helping Others <u>Through</u> P Engagement	Purpose &

A Handbook for Supervising Volunteers with Traumatic Brain Injury (TBI)



Figure 2. HOPE handbook table of contents.pdf.

ontents	
The Benefits of Volunteering	
What it Means to be a Volunteer	
Successful Volunteering After TBI	
Challenges to Successful Volunteering after TBI	
Strategies for Successful Volunteering After TBI	
Problem Solving in Your Volunteer Agency	
Your Rights as a Volunteer	
Summary	
References	
My Volunteer Plan	
My Calendar	

Contents
Understanding Traumatic Brain Injury (TBI)
Types of TBI
Common Challenges Following Moderate/Severe TBI
Long-Term Challenges Which May be Problematic in a Work/Volunteer Setting
A Special Note about Military Veterans with TBI
Setting the Stage for Successful Engagement of Volunteers with TBI
Do I ask about the injury?
How should I interact with someone with a TBI?
What are some general strategies I can use to help the volunteer be successful ⁹ ?
Summary of Strategies for a Successful Environment
Helpful resources
Sample Volunteer Plan (as provided in the HOPE Handbook)
References

Author Manuscript

Author Manuscript

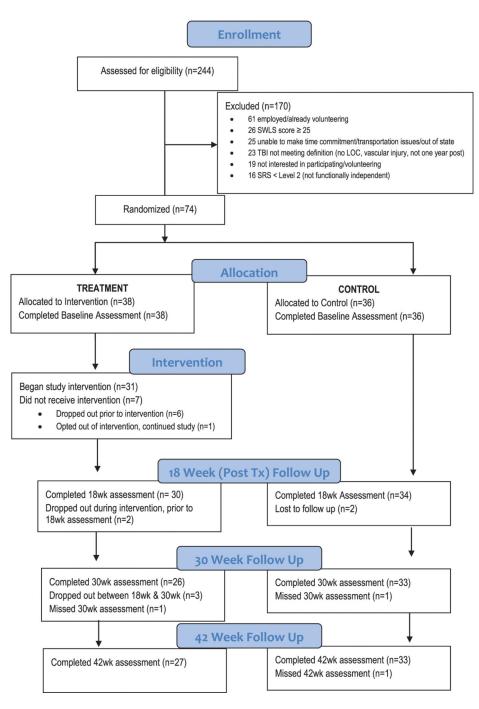
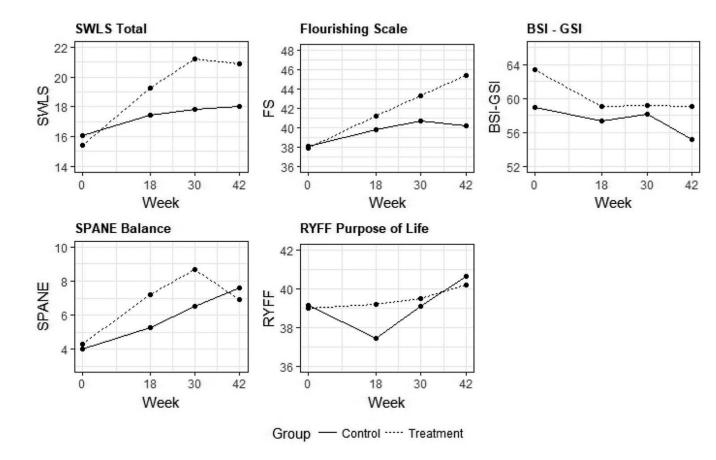


Figure 3.

Consort flow reporting diagram.

Payne et al.



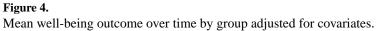


Table 1.

Inclusion and exclusion criteria.

Inclusion Criteria

• Sustained a TBI as defined by damage to brain tissue caused by an external mechanical force as evidenced by a loss of consciousness or post-traumatic amnesia (PTA) due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination

• Ability to provide documentation of TBI either by medical records or a written confirmation by a licensed health-care provider qualified to make the diagnosis

- Received inpatient or outpatient TBI rehabilitation treatment
- At least 1-year post-TBI
- Age 18 or older
- · Ability to commit to completing the entire 3-month volunteer placement
- English or Spanish speaking
- Rated a level 1-2 on the Supervision Rating Scale (functionally independent during the day)
- · Provide informed consent to participate

Exclusion Criteria

- Employed or engaged in regularly scheduled volunteer work outside of the intervention for more than 3 weeks during the study
- Obtained a score of 25 or above on the Satisfaction with Life Scale (SWLS) indicating high life satisfaction
- · Unable to travel to assessments and placement; even with study transportation assistance
- Completed the pilot study of this intervention
- · Cognitive impairment that precludes completion of baseline testing
- · Any reason that in the opinion of the principal investigators might interfere with completion of the protocol

Table 2.

Summary of sample characteristics at baseline.

		Treatment (<i>N</i> = 38)		Control $(N = 36)$
	N	Mean (SD)/ Median (IQR)	N	Mean (SD)/ Median (IQR
Age at Baseline, Mean (SD)	38	48.1 (12.0)	36	48.1 (11.8)
Years Since Injury, Median (IQR)	38	5.0 (2.0–14.0)	36	7.5 (2.0–17.0)
	N	Percent	N	Percent
Sex				
Male	17	44.7	19	52.8
Female	21	55.3	17	47.2
Race/Ethnicity				
White	26	68.4	28	77.8
Not White	12	31.6	8	22.2
Current Level of Education				
HS or Lower	9	23.7	9	25.0
Some College	15	39.5	18	50.0
Bachelor's Degree or Higher	14	36.8	9	25.0
Employment Status at Injury				
Employed Full Time	24	63.2	23	63.9
Not Employed Full Time	14	36.8	13	36.1
Current Marital Status				
Single	10	26.3	14	38.9
Married	14	36.8	9	25.0
Divorced	14	36.8	13	36.1
Household Income				
Less than \$25,000	19	54.3	19	57.6
\$25,000-\$49,999	7	20.0	4	12.1
\$50,000-\$99,999	4	11.4	5	15.2
\$100,000 or More	5	14.3	5	15.2
(Missing)	(3)		(3)	
Current Residence				
Private	38	100.0	34	94.4
Adult Home	0	0.0	2	5.6
Current Living Situation				
Alone	13	34.2	14	38.9
Spouse/Significant Other	14	36.8	9	25.0
Parent(s)	8	21.1	9	25.0
Other	3	7.9	4	11.1
Cause of Injury				
Motor Vehicle/Motorcycle/Bicycle	24	63.2	27	75.0

		Treatment (<i>N</i> = 38)		Control (<i>N</i> = 36)
	N	Mean (SD)/ Median (IQR)	N	Mean (SD)/ Median (IQR
Age at Baseline, Mean (SD)	38	48.1 (12.0)	36	48.1 (11.8)
Years Since Injury, Median (IQR)	38	5.0 (2.0-14.0)	36	7.5 (2.0–17.0)
	N	Percent	N	Percent
Fall/Hit by Falling/Flying Object	9	23.7	5	13.9
Pedestrian/Violence/Sports	5	13.2	4	11.1

SD = standard deviation; IQR = Interquartile range.

Changes in well-being outcomes from baseline.

	Endpoint	Estimate	SE	95% CI	<i>p</i> -value		ES
Satisfaction with Life Scale	e						
$s^2 = 44.52, r = 0.68$							
Treatment × Time: F (3, 182) = 3.55, <i>p</i> -value = 0.0157	2) = 3.55, <i>p</i> -valu	ie = 0.0157					
Treatment	18 Week	3.86	0.95	(1.98, 5.75)	<0.0001	4	0.58
Control	18 Week	1.40	0.91	(-0.38, 3.19)	0.1228		0.21
Treatment - Control	18 Week	2.46	1.32	(-0.14, 5.06)	0.0632		0.37
Treatment	30 Week	5.78	1.00	(3.80, 7.77)	<0.0001	*	0.87
Control	30 Week	1.77	0.91	(-0.04, 3.57)	0.0550		0.27
Treatment - Control	30 Week	4.02	1.36	(1.34, 6.70)	0.0035	\$	0.60
Treatment	42 Week	5.48	0.99	(3.52, 7.44)	<0.0001	4	0.82
Control	42 Week	1.95	0.91	(0.14, 3.75)	0.0344	4	0.29
Treatment - Control	42 Week	3.53	1.35	(0.87, 6.19)	0.0096	s	0.53
Flourishing Scale							
$s^2 = 59.84, r = 0.56$							
Treatment × Time: F (3, 181) = 2.88, <i>p</i> -value = 0.0372	1) = 2.88, <i>p</i> -valu	le = 0.0372					
Treatment	18 Week	3.30	1.33	(0.67, 5.93)	0.0141	*	0.40
Control	18 Week	1.64	1.24	(-0.81, 4.09)	0.1870		0.20
Treatment - Control	18 Week	1.66	1.82	(-1.94, 5.25)	0.3640		0.20
Treatment	30 Week	5.35	1.39	(2.61, 8.09)	0.0002	4	0.66
Control	30 Week	2.54	1.25	(0.07, 5.01)	0.0443	*	0.31
Treatment - Control	30 Week	2.81	1.87	(-0.88, 6.50)	0.1349		0.34
Treatment	42 Week	7.43	1.37	(4.73, 10.13)	<0.0001	4	0.91
Control	42 Week	2.08	1.25	(-0.39, 4.56)	0.0980		0.26
Treatment - Control	42 Week	5.35	1.86	(1.68, 9.01)	0.0045	\$	0.66
BSI-GSI							
$s^2 = 99.71, r = 0.73$							
Treatment × Time: F (3, 181) = 1.52, <i>p</i> -value = 0.2120	1) = 1.52, p-valu	le = 0.2120					
Treatment	18 Week	-4.36	1.34	(-6.99, 1.72)	0.0013	*	-0.44

	Endpoint	Estimate	SE	95% CI	<i>p</i> -value		ES
Control	18 Week	-1.53	1.27	(-4.03, 0.97)	0.2284		-0.15
Treatment - Control	18 Week	-2.83	1.84	(-6.46, 0.81)	0.1265		-0.28
Treatment	30 Week	-4.19	1.41	(-6.97, -1.42)	0.0033	4	-0.42
Control	30 Week	-0.79	1.28	(-3.31, 1.74)	0.5398		-0.08
Treatment - Control	30 Week	-3.41	1.90	(-7.16, 0.34)	0.0747		-0.34
Treatment	42 Week	-4.38	1.39	(-7.12, -1.65)	0.0019	*	-0.44
Control	42 Week	-3.70	1.28	(-6.22, -1.17)	0.0043	4	-0.37
Treatment - Control	42 Week	-0.69	1.89	(-4.41, 3.04)	0.7158		-0.07
SPANE Balance							
$s^2 = 39.72, r = 0.46$							
Treatment × Time: F $(3, 183) = 1.27$, <i>p</i> -value =	83) = 1.27, <i>p</i> -valu	e = 0.2865					
Treatment	18 Week	2.91	1.17	(0.60, 5.23)	0.0140	*	0.46
Control	18 Week	1.28	1.12	(-0.93, 3.49)	0.2550		0.20
Treatment - Control	18 Week	1.63	1.62	(-1.57, 4.84)	0.3160		0.26
Treatment	30 Week	4.37	1.24	(1.93, 6.81)	0.0005	*	0.69
Control	30 Week	2.52	1.13	(0.29, 4.75)	0.0272	*	0.40
Treatment - Control	30 Week	1.85	1.68	(-1.46, 5.16)	0.2710		0.29
Treatment	42 Week	2.61	1.20	(0.23, 4.98)	0.0318	*	0.41
Control	42 Week	3.58	1.13	(1.34, 5.81)	0.0019	*	0.57
Treatment - Control	42 Week	-0.97	1.65	(-4.23, 2.29)	0.5584		-0.15
Ryff Purpose in Life							
$s^2 = 49.25, r = 0.51$							
Treatment × Time: F (3, 178) = 0.58, <i>p</i> -value = 0.6288	78) = 0.58, <i>p</i> -valu	e = 0.6288					
Treatment	18 Week	0.18	1.24	(-2.26, 2.62)	0.8855		0.03
Control	18 Week	-1.68	1.20	(-4.05, 0.70)	0.1654		-0.24
Treatment - Control	18 Week	1.85	1.73	(-1.55, 5.26)	0.2840		0.26
Treatment	30 Week	0.49	1.30	(-2.08, 3.05)	0.7097		0.07
Control	30 Week	-0.03	1.22	(-2.43, 2.37)	0.9819		0.00
Treatment - Control	30 Week	0.51	1.78	(-3.00, 4.03)	0.7737		0.07
Treatment	42 Week	1.20	1.32	(-1.40, 3.80)	0.3648		0.17
Control	42 Week	1.50	1.23	(-0.93, 3.92)	0.2245		0.21

Brain Inj. Author manuscript; available in PMC 2021 November 29.

Payne et al.

Author Manuscript

	Endpoint	Estimate	SE	95% CI	<i>p</i> -value	ES
Treatment - Control	42 Week	-0.30	1.80	(-3.85, 3.26)	0.8689	-0.04

to endpoint (within group) or the mean difference in the changes from baseline to endpoint (between groups); CI = Confidence Interval; $ES = Effect Size = estimate/sqrt [(\sigma^2 residual + \sigma^2 subject)]$ \dot{x} Statistically significant ($\alpha = 0.05$) for within-group changes; Statistically significant ($\alpha = 0.0167$) for comparison of changes between groups; Estimate represents the mean change from baseline model-based estimate of pooled SD; s^2 = estimated variance; r = estimated correlation among repeated measures.

Payne et al.