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## Social Participation and Navigation with Adolescent and Young Adult Brain Tumor Survivors: Usability and Potential Benefits

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# Social Participation and Navigation with Adolescent and Young Adult Brain Tumor Survivors: Usability and Potential Benefits

## Abstract

*Background:* This study examined the usability and potential benefits of Social Participation and Navigation (SPAN), a virtual coaching goal planning intervention, which was modified for adolescent and young adult (AYA) brain tumor survivors who often experience social participation challenges.

*Methods:* Four AYA brain tumor survivors participated in a brief trial of the modified SPAN consisting of four weekly coaching sessions with trained supervised occupational therapy graduate students and use of a website and web application to assist with goal planning and achievement. The participants rated their social participation and SPAN-specific skills pre/post program. The participants and parents completed 1-week and 1-month usability surveys post program. Effect sizes were computed to examine pre/post score changes. Descriptive statistics and content analyses were used to examine quantitative and qualitative usability data.

*Results:* SPAN was well-received by the AYAs, parents, and coaches with high satisfaction ratings for coaching. All participants achieved at least one goal. The participants had increased post-intervention scores in social participation (overall, school, community) and SPAN skills (goal planning, self-regulation, reciprocal communication). Suggestions for improvement primarily focused on the SPAN web application.

*Conclusion:* The results demonstrated the usability and potential benefits of SPAN for AYA brain tumor survivors and have informed a larger implementation trial.

## Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

## Keywords

brain injury, coaching, social participation, youth

## Cover Page Footnote

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## Credentials Display

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Brain tumors are the second most common type of childhood cancer, accounting for about 20% of cases, with an overall incidence of approximately 4.5 cases in 100,000 (Wolfe et al., 2013). When compared to survivors of other pediatric cancers, adolescent and young adult (AYA) survivors of childhood brain tumors are more likely to experience physical, cognitive, and psychosocial impairments and are less likely to be employed (Chow et al., 2018; Gurney et al., 2009). These impairments and other factors, including frequent hospitalizations, treatment side-effects, and the uncertainty around the future associated with cancer treatment and survival, can result in social isolation and depression as well as decreased engagement in important life roles and development and maintenance of relationships (Carpentieri et al., 2003; Hocking et al., 2015; Shulte et al., 2010; Ullrich et al., 2012).

AYAs with pediatric onset brain tumors and other acquired brain injuries (ABI) often experience limitations in their social participation. Social participation can be described as taking part in activities that involve social interactions with others, such as spending time with friends or family or talking with a co-worker (Bedell, 2012). Social participation in AYAs has been associated with community outcomes in adulthood, such as independent living and employment (Bedell et al., 2013). As social participation is an integral part of many aspects of life, including work, school, family, and the community, these limitations can occur in many settings and affect many areas of their life, manifesting as social isolation, lack of meaningful friendships, and exclusion from social opportunities (Anaby et al., 2012; Bedell & Dumas, 2004).

### **Social Participation Interventions**

There is limited evidence specific to interventions that promote the social participation of AYA brain tumor survivors. However, some evidence from feasibility and pilot studies demonstrating small-to-moderate effect sizes does exist to suggest that group interventions may be successful in improving social skills for brain tumor survivors between 7 and 18 years of age (Barakat et al., 2003; Barrera & Schulte, 2009; Schulte et al., 2014). These group-based interventions, often provided in hospital-based settings, include practice and training in social initiation, making friends, cooperation, conflict resolution, and managing teasing and bullying via roleplaying and other group or dyadic activities. In one intervention study, Shulte et al. (2014) reported promising results related to improved selected social skills (such as maintaining eye contact in conversations); however, social problem-solving skills did not improve. To address social problem-solving skills, some suggest that social skills training programs need to focus on improving executive functioning skills as well (e.g., self-regulation, problem-solving, and cognitive flexibility) because of the bidirectional association of executive function skills and social skills (Wolfe et al., 2013).

Recently, an online problem-solving intervention (“Survivors Journey”) was developed for AYA brain tumor survivors 13 to 25 years of age (Wade et al., 2019). The intervention involved self-guided web modules focusing on problem-solving to cope with everyday life challenges and weekly one-on-one teleconferences with a trained therapist. Although this program did not target social participation directly, preliminary effects showed quality-of-life improvements for survivors but no improvements in executive functioning. Wade et al. (2019) reported a need for further study and tailoring of the program to address the different needs of adolescent and young adult participants.

A recent scoping review of interventions that address social participation outcomes of AYAs with social and executive functioning challenges found that the evidence available is constrained by inconsistent conceptualization and operationalization of social participation, small sample sizes, and lack of experimental controls (O’Rourke et al., 2020). However, of the 32 intervention studies appraised, two

dominant and promising intervention types emerged: peer mentoring/coaching and social skills training. Person-centered goal planning and practice in the participants' daily lives and natural environment, core components of occupational therapy practice, were also identified as potentially beneficial intervention components in this review (O'Rourke et al., 2020). Social Participation and Navigation (SPAN) is one promising intervention that includes some of these key intervention elements (Wade et al., 2018). SPAN is a remotely delivered person-centered peer coaching intervention that was initially designed for teenagers with traumatic brain injury to support social participation goal achievement (Bedell et al., 2017; Narad et al., 2018; Wade et al., 2018).

### **SPAN Overview**

The main components of SPAN are virtual coaching sessions with college student coaches, coach training and weekly supervision, tips and topics, and a goal planning application that is now housed on a new website (<https://spanprogram.com/>). Additional tips and topics (i.e., time management and social communication) not currently on the website were also created based on feedback from our prior SPAN study (Wade et al., 2018) and were available to coaches and participants in this study if requested or needed.

Trained college student coaches are paired with a participant in the program and use coaching principles, such as active listening, to build rapport and get to know the participants. In addition to modeling and facilitating social interaction in the sessions, coaches support participants in the goal-planning process involving the Goal, Plan, Do, Review framework (Wade et al., 2018). In this framework, the participant identifies a goal (Goal) and then creates a plan to achieve the goal using steps and strategies (Plan). The participant then implements the plan outside of the sessions (Do), reflects on their progress, and modifies the plan, if necessary, with their coach in the following sessions (Review). Coaches also provide onboarding and scaffolding to assist participants in using the SPAN web-based goal planning app. The participants are given a password and username to access the app and can enter their goals and the steps needed to achieve each goal with corresponding due dates. Email reminders are sent through the SPAN app when the due date designated for a step is nearing. The participants could mark a step or goal as completed as well. The app also includes a strategy bank where participants can enter strategies that are generated and used to achieve each goal and re-purposed for other goals.

Promising results were found in a 10-week implementation trial of SPAN with 13 teenagers with acquired brain injuries (TBI,  $n = 9$ ; brain tumor,  $n = 4$ ) related to goal achievement and selected measures of social functioning and participation (Wade et al., 2018). Challenges were identified with the goal planning mobile app, so the new website with online tips and topics and a web-based goal planning app was developed. Also, parents of teenagers with brain tumor survivors reported that more content and training needed to be tailored to their children's needs, given that SPAN was initially informed by stakeholders with or affected by TBI.

The overall purpose of this study was to examine the usability and potential benefits of SPAN using a version modified for AYA brain tumor survivors (15 to 23 years of age). This brief usability trial included a shortened 4-week version of the SPAN program while maintaining the same components and structure as the 10-week version (Wade et al., 2018). The specific study aims were to examine (a) pre to post trial score changes on measures of social participation and SPAN-specific skills (e.g., goal planning, self-regulation, and reciprocal communication); (b) social participation goal achievement; and (c) participant perceptions on ease of use, usefulness, and likelihood of continued use of SPAN and suggestions for improvement.

## Method

This study was part of a more extensive study to modify and assess the SPAN's usability and potential benefits for AYA brain tumor survivors. The research was a collaboration between one university in the Northeast USA and the Northeast region of a national organization that serves AYA brain tumor survivors and their families. The university's institutional review board approved the study.

The current study was a brief 4-week usability trial of the modified version of SPAN using a similar design as the prior SPAN usability study conducted with teenagers with TBI (Narad et al., 2018). Before this study, key stakeholder feedback (two adolescent and two young adult survivors, one parent of a survivor, and SPAN research team members) was gathered to inform modifications of the SPAN program that are relevant to the needs of AYA brain tumor survivors. Based on this feedback and prior feedback from adolescent brain tumor survivors and their parents in a previous study (Wade et al., 2018), we modified the coach training guidelines and increased the length of coach training for practice, feedback, and readings. We included additional brain tumor content (handouts, strategies, and video clips of AYA survivors talking about their lived experiences, challenges, and aspirations). We also modified the SPAN measures for use in this study to be more tailored to the intervention (which included additional aspects of social participation and skills focused on in SPAN), more strengths-based and less problem-based, and more community versus clinical-oriented.

### Recruitment

Email correspondences were sent to local hospitals and programs that provide services to AYA brain tumor survivors living or receiving services in and around a large city in the Northeast USA. These emails contained information about the present study and asked coordinators at these locations to relay the information to potential participants and families. In addition, information about recruitment for the study was posted on social media associated with the organization serving AYA survivors. Inclusion criteria were being between 15 to 23 years of age, having been diagnosed with a brain tumor before 18 years of age, being at least 6 months post brain tumor treatment, and exhibiting social participation challenges. Exclusion criteria were not being proficient in English; a diagnosis of a developmental cognitive impairment; severe developmental disability; a diagnosis of a developmental social disorder, like autism spectrum disorder; a diagnosis of a severe behavioral or psychiatric condition; or psychiatric hospitalization within the last 12 months. The participants who were interested and eligible were given further descriptions of the study. Those who wished to participate completed informed consent and assent via a Zoom call with research assistants.

### Coach Training and Supervision

Two occupational therapy graduate students were provided with coaching training before working with the participants and then weekly coach supervision while working with the participants. Coaches reviewed training materials and went through multiple training sessions that included lecture-based presentations from the two coach supervisors (one occupational therapist and one social worker), as well as coaching practice and feedback sessions with each other (each taking the role of coach and participant). Training sessions and supervision were conducted remotely via Zoom. The coaches were randomly paired with their participants (two participants per coach) and were responsible for onboarding the participants onto the SPAN program, supporting the development of social participation goals, and providing relevant resources within SPAN to the participants and their families. Further, the coaches recorded detailed notes of each session. These coach session notes were used to inform weekly group supervision meetings with

the coach supervisors and to inform weekly email messages sent to the parents of the adolescent participants.

### Procedure

The participants virtually completed the SPAN questionnaire to measure social participation levels across different social domains and settings. The research assistants shared their screens via Zoom and read each prompt, and the participants were instructed to respond based on what they believed best described their levels of involvement and confidence. In addition, the participants were asked to identify supports and barriers to their social participation. Once the questionnaire was completed, the research assistants sent a copy of the responses to the participants and their respective coaches. The coaches then emailed the participants and/or parents to schedule the first coaching session.

There were four virtual coaching sessions for each participant, each lasting between 45 to 60 min. A summary of the general timeline for the brief usability trial can be found in Table 1; however, in some cases, specific activities may have been done and repeated in different weeks based on each of the participant's distinct needs.

**Table 1**

*Usability Trial Timeline Overview*

<b>Pre coach Sessions</b>	<b>Informed consent/assent and completion of the SPAN-specific pre questionnaire via Zoom with the research assistant.</b>
<b>Session 1:</b>	Introductions, description of program logistics, tour of website features, review SPAN-specific pre questionnaire answers and building rapport.
<b>Session 2:</b>	Reviewing the goal, plan, do, review framework, goal development, and development of a plan.
<b>Session 3:</b>	Supporting the implementation of the plan and reviewing progress.
<b>Session 4:</b>	Review of goal progress/attainment, encouraging continued use of developed skills, and closure.
<b>Post coach Sessions:</b>	Completion of the SPAN-specific post questionnaire via Zoom with research assistant. Usability feedback survey sent 1 week after completion of coaching to parents and AYAs. One-month follow-up survey sent to the parents and AYAs 1 month after completion of the coaching and SPAN-specific post questionnaire.

### Measures

#### *The SPAN Questionnaire*

The SPAN questionnaire is a self-report measure used in the initial trials of SPAN and modified for use in this study. The questionnaire examines two areas: (a) social participation and (b) self-efficacy specific to skills being addressed in SPAN. The social participation component consists of 30 items focusing on social participation in multiple domains, including social media (two items), home and family (eight items), school participation (seven items), and community (including work) (13 items). For each item, the participants rated two dimensions of social participation, involvement, and confidence, with separate 5-point ratings for involvement (1 = *not involved*, 2 = *minimally involved*, 3 = *fairly involved*, 4 = *involved*, 5 = *extremely involved*) and for confidence (1 = *not confident*, 2 = *minimally confident*, 3 = *fairly confident*, 4 = *confident*, 5 = *extremely confident*). In addition, the participants were asked to provide explanations for any item they rated as minimally involved or lower, as well as describe any barriers or supports to their participation. The SPAN skills self-efficacy portion consisted of 15 items related to goal planning (five items), self-regulation (six items), and reciprocal communication (four items). The participants rated their confidence in these areas on a 5-point scale (1 = *not confident*, 2 = *minimally confident*, 3 = *fairly confident*, 4 = *confident*, 5 = *extremely confident*). Percent of Maximum Possible (POMP) scores were computed for overall total scores and subsection scores on the SPAN questionnaire. The POMP score is the sum of all applicable items divided by the maximum possible score and then multiplied by 100.

Preliminary analyses were conducted to examine internal consistency (via Cronbach's  $\alpha = \alpha$ ) of the three SPAN questionnaire scales based on data from 24 SPAN questionnaires completed by AYA brain tumor survivors. The results from these analyses were found to be very good to excellent: Social Participation Involvement ( $\alpha = .86$ ), Social Participation Confidence ( $\alpha = .95$ ), and SPAN Skills Self-Efficacy ( $\alpha = .92$ ). Internal consistency of the social participation setting-specific subsections was fairly good to excellent: home & family (Involvement,  $\alpha = .78$ ; Confidence,  $\alpha = .91$ ); school (Involvement,  $\alpha = .68$ ; Confidence,  $\alpha = .90$ ); community (Involvement,  $\alpha = .80$ ; Confidence,  $\alpha = .85$ ). In addition, internal consistency for the three SPAN Skills Self-Efficacy subsections were found to be good to excellent: goal planning ( $\alpha = .87$ ), self-regulation ( $\alpha = .91$ ), and reciprocal communication ( $\alpha = .78$ ).

### **Usability Survey**

One week after completion of the final coaching session, the AYA participants and their parents were sent an online Qualtrics usability survey that included questions about the technical aspects of the SPAN web-based goal planning application (app); the usefulness of the SPAN features; and the tips, topics, coaching, and duration of the program. The participants were asked to rate the ease of use for different aspects of the SPAN web app on a 4-point scale (1 = *difficult*, 2 = *somewhat difficult*, 3 = *easy*, 4 = *very easy*). The participants were then asked to rate the usefulness and likelihood of continued use of aspects of the SPAN web application (user profile, creating goals, creating steps, listing strategies, overall tips, overall topics, and each tip/topic) on two 4-point scales (1 = *not at all useful/likely*, 2 = *fairly useful/likely*, 3 = *useful/likely*, 4 = *very useful/likely*). In addition, the participants rated their agreement or disagreement with various statements categorizing the coaching experience on a 6-point Likert scale (1 = *strongly disagree*, 2 = *somewhat disagree*, 3 = *disagree*, 4 = *agree*, 5 = *somewhat agree*, 6 = *strongly agree*). The participants were then asked to rate whether the 4 weeks were enough time and to provide open-ended feedback about the program.

### **One-Month Follow-Up Survey**

One month after completion of the final coaching session, the AYA participants and their parents were sent an online Qualtrics survey to assess continued use of and experiences related to specific aspects of the program. The participants were asked about their social participation experiences and their continued use of goal planning, the SPAN web-based application, and the skills and knowledge learned in the sessions. The parents of adolescents were asked about their own and their family's involvement and their perception of their child's continued social participation. The participants also provided additional feedback and suggestions about the SPAN program and additional supports and resources that might be needed.

### **Coach Feedback Survey**

Following the completion of their final session, each of the two coaches completed an open-ended survey about their experience as a SPAN coach, thoughts on the program design, and suggestions for improvement. The coaches provided feedback on what was and was not useful, the challenges they encountered, and what they would suggest improving before implementing a larger trial.

### **Data Analysis**

Descriptive statistics were used to characterize the sample and to analyze the quantitative survey responses from the subsections and item-level responses on the pre and post SPAN program-specific questionnaires. Effect sizes (Cohen's  $d$ ) were used to compare changes from pre to post on the SPAN-specific questionnaire total and subsection scores. Descriptive statistics were used to analyze the quantitative responses to the usability survey. Content analysis was used to analyze open-ended responses

from the 1-week usability and 1-month follow-up surveys, pre and post SPAN program-specific questionnaires, as well as the coach session notes and coach feedback surveys. The open-ended responses were examined to identify and organize key information provided across the participants and through these multiple data collection methods.

## Results

### Participants

The sample for this study consisted of four AYA brain tumor survivors: two adolescents and two young adults. Two of the participants identified as female, and two identified as male. Their ages ranged from 15 to 23 years, and their diagnoses ages ranged from 3.5 months to 11 years. Of the four participants, all identified as White, and one also identified as Hispanic.

### Goal Achievement Summary

Table 2 shows a summary of the type of goals developed by the participants. All four of the participants developed social participation goals with goal areas focused on: (a) social relationships and/or getting together with others, (b) joining new groups/trying new roles, and (c) preparing for social activities. One participant developed four goals across the 4-weeks, and the other three each developed two goals. All four of the participants achieved at least one of their goals. One participant increased the difficulty of their goal midway through the program and achieved their initial goal, with the expanded goal remaining unattained by the end of the program. Two goals were marked as complete in the case where the participant did not achieve the exact goal that was planned but rather a different goal that was similar enough that they deemed the goal achieved (i.e., becoming more involved in the decision-making for an activity, or performing the goal in a different setting from initially specified in the plan).

**Table 2**  
*Summary of Goals Developed*

Type of goal	Number of goals developed	Number of completed goals	Number of goals planned / working on
Social Relationships / Get Togethers	4	3	1
New Group / Role	4	1	3
Preparing for Social Activities	2	1	1
Total	10	5	5

### Social Participation Involvement and Confidence Scores

Table 3 summarizes the pre/post means, standard deviations, and effect sizes (Cohen's d) for the social participation total score and subsection scores (home and family, school, and neighborhood and community). Overall total social participation scores increased with medium (involvement) and approximately medium (confidence) effect sizes. Home and family scores decreased with large (involvement) and medium (confidence) effect sizes. School scores increased with large (involvement) and small (confidence) effect sizes. Community scores increased with very large (involvement) and large (confidence) effect sizes.

### SPAN-Related Skills Self-Efficacy Scores

Table 4 summarizes the pre/post means, standard deviations, and effect sizes (Cohen's d) for the SPAN-related skills self-efficacy scores. Overall confidence increased with very large effect sizes for the total score and self-regulation and reciprocal communication subsection scores and an essentially large effect size for the goal planning subsection score.

**Table 3***Social Participation Involvement and Confidence Scores*

Scores	Pre SPAN Mean (SD)	Post SPAN Mean (SD)	Effect Size (Cohen's d)
<i>Overall Social Participation</i>			
Involvement	65.91 (3.40)	68.54 (5.33)	0.60
Confidence	77.82 (8.55)	81.36 (7.10)	0.45
<i>Home and Family</i>			
Involvement	87.5 (8.42)	78.13 (9.44)	-1.05
Confidence	93.75 (4.79)	87.50 (13.54)	-0.68
<i>School</i>			
Involvement	55.24 (16.74)	65.71 (8.57)	0.83
Confidence	71.43 (24.91)	77.14 (4.95)	0.38
<i>Neighborhood and Community</i>			
Involvement	55.00 (7.68)	63.09 (3.77)	1.41
Confidence	68.46 (12.08)	76.54 (7.04)	0.84

**Table 4***SPAN-Related Skills Confidence Scores*

Scores	Mean (SD) Pre test	Mean (SD) Post test	Effect Size (Cohen's d)
Overall - Total	76.00 (5.22)	84.00 (3.61)	1.81
Goal Planning	76.00 (11.78)	85.00 (11.02)	0.79
Self-regulation	74.17 (3.19)	81.67 (5.77)	1.67
Reciprocal Communication	78.75 (6.29)	86.25 (4.79)	1.35

**Identified Supports and Barriers**

Questions examining perceived supports and challenges in the participants' social participation were explicitly asked in the SPAN questionnaire. In addition, the coaches further explored supports and challenges that were currently being encountered by the participants during the coaching sessions. Table 5 identifies the key supports and challenges and the number of participants who reported these on the SPAN questionnaire and/or during the coach session. All of the participants mentioned the support of their family or other adults in the success of their social participation goals. One participant noted that their family members were most helpful with reminders to complete goal steps, whereas another participant relied on their teachers to bridge social connections between them and their peers. In addition, the participants shared that having familiarity with the environment, activity, or people further supported their ability to engage with others. When asked about barriers or challenges, the participants pointed to specific impairments associated with their condition, such as memory challenges. Most of the participants also noted that others' negative perceptions of about their impairments led to further anxiety about social participation. Other common challenges included logistical barriers, such as a limitation in social opportunities because of the COVID-19 pandemic and scheduling challenges with friends.

**Table 5***Summary of Supports and Challenges*

Supports	Participants reporting	Challenges	Participants reporting
Family/Adult support	4	COVID	3
Familiarity of environment/People	2	Scheduling issues	3
Self-confidence/Personality	2	Condition-specific limitations	2
Groups/Community activities	1	Anxiety/nervousness	1
Deep breathing exercises	1	Limited friends in area	1

**Coach Feedback**

Overall, coaches provided positive feedback on their program participation and valuable suggestions for improvement. For the coach training prior to the coaching sessions, the coaches suggested breaking down the training into multiple sessions and allowing for outside practice time, as well as providing specific information on brain tumor survivors. Coaching supervision meetings were generally well-received, with the only suggestion being to lengthen the sessions to allow for more time to discuss when there are more coaches in the subsequent larger 10-week implementation trial. Coaches also stated that the handout materials, including the tips and topics, were beneficial to refer to in the early sessions, but they needed to remind the participants frequently that the tips and topics were accessible to them

independently through the website. In addition, coaches reported that completing the coach session notes supported them in reflecting on the session details and reviewing the session during supervision. The web application was reported to be an area of challenge for coaches, as the participants sometimes experienced technical difficulties and did not remember to use the website unless reminded. However, coaches reported that the goal planning and the due date and reminder functions of the app were very helpful. Overall, the coaches reported that the structure of the sessions was good, and the hour-long session time allowed for rapport building before working on more formalized SPAN materials. Coaches suggested that more sessions would be beneficial to get more in-depth with goals with the participants and that the time of year may play a role in the level of social participation the participants engage in (as this brief usability trial occurred during the summer months).

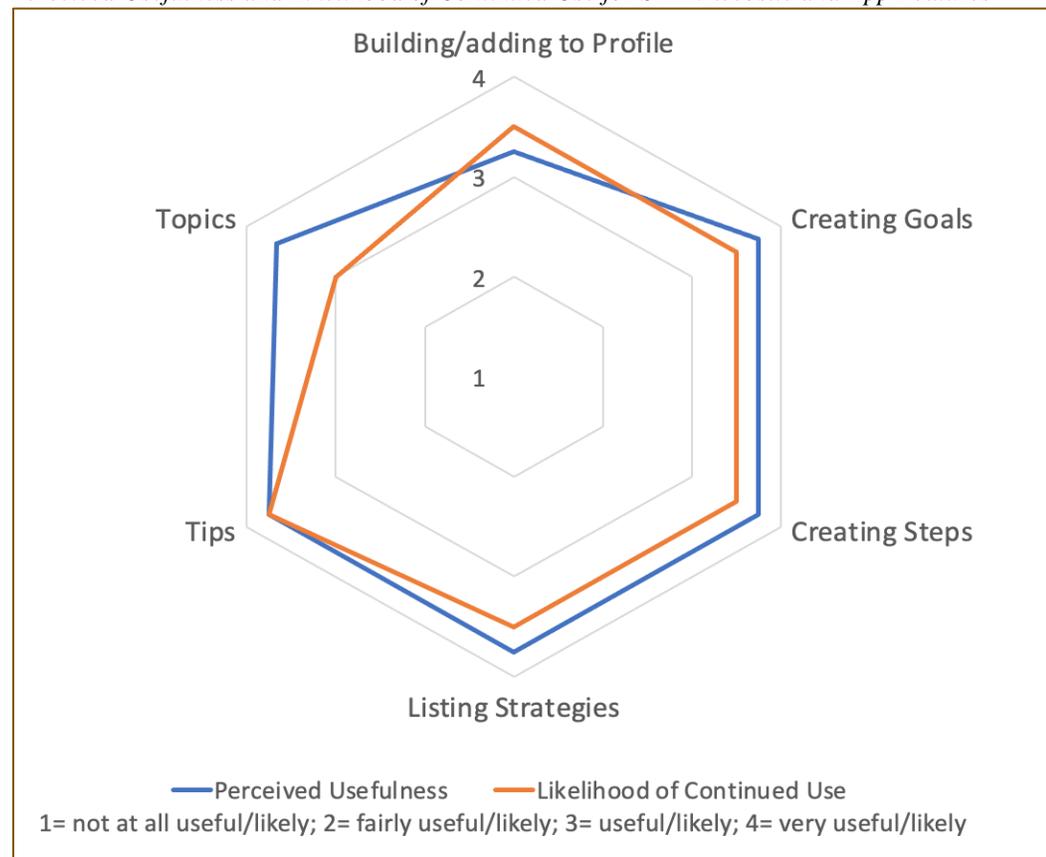
## Online Usability Survey Results

### One-Week Usability Survey

The AYA participants rated six aspects of the program related to usefulness and the likelihood of continued use, as shown in Figure 1. On average, the participants found each component useful/very useful and would be likely/very likely to engage with these six aspects after completing the brief usability trial. The participants rated the overall tips and topics sections as equally useful but rated the tips as more likely to continue to use than the topics. In addition (but not noted in Figure 1), the participants rated the perceived usefulness and likelihood of continued use for each of the five tips and four topics found on the SPAN website, with average ratings ranging between a three and a four (*useful/likely* and *very useful/likely*).

**Figure 1**

*Perceived Usefulness and Likelihood of Continued Use for SPAN Website and App Features*



When asked about their experience with the virtual coaching sessions, the AYA participants strongly agreed with all statements (e.g., “I enjoyed my coaching session,” “I felt heard, understood, and respected by my coach”). Open-ended responses also showed overall support for the coaching aspects of SPAN, especially related to the development of steps and strategies to achieve goals. Many of the participants identified that they found breaking the goal down into smaller steps was useful and that they got support from family or other adults in their lives to reach their goals. The participants reported difficulties with the SPAN web app, including difficulties entering and saving goal steps and difficulties logging in to the website. The participants recommended that revisions be made to the SPAN web app to make it more accessible on mobile devices and the addition of other features to the app, including a calendar reminder section.

The two parents of the adolescent participants completed the online 1-week follow-up usability survey. Overall, parents rated program features, including the goal planning application, coaching, and tips and topics, positively, similarly to their children. The parents reported that the most beneficial aspects of the program for their children were the ability to work on setting goals and reviewing the goals with their coach. The parents reported that the most challenging aspects of the program related to working toward goals during the summertime (as the school setting provides more opportunities for social participation) and their child’s stamina to participate in sessions with the coach and to work toward goal achievement. Parental recommendations focused on adapting the program to allow for the ability for the parents and coach to connect more directly to better support the participant in reaching their goals (i.e., rather than through weekly emails sent to parents by one of the coach supervisors).

### *One-Month Follow-Up Survey*

Of the initial four AYA participants who were part of the program, three responded to the 1-month follow-up survey. All three participants identified that in the month following the completion of the program, they continued to work toward the goals they developed in the SPAN program and continued to use the SPAN web-based goal planning app and the tips and topics sections on the website. Strategies identified to achieve their goals included attending more events, time management strategies, and setting times to connect with friends. All of the participants reported that they asked their families to help support their social participation, mainly in the areas of time management and planning. They all reported that they intended to continue to use the SPAN website and app in the future to help with goal setting, memory supports, and time management skills. Of the three participants surveyed, two reported they would have liked to have continued with their coaching sessions.

One of the two parents of adolescent participants completed the 1-month follow-up survey. This parent reported that their child was continuing to work on social participation goals and that they would have liked their child to have continued with additional coaching sessions to help support goal achievement and progress.

### **Discussion**

The results of this study preliminarily support the usability and feasibility of SPAN for AYA brain-tumor survivors. Overall, the brief trial of SPAN was received well by AYA survivors, parents, and coaches, with suggestions for modifications mostly focusing on app-related accessibility and interface and duration of the program. The goal planning and coaching aspects of SPAN were particularly well-liked by the participants. The 1-month follow-up also demonstrated the potential long-term benefits of engagement in SPAN with continued use of learned skills, such as goal planning, time management, and social communication skills.

The fact that peer coaching was well-received and deemed valuable by the participants and parents was not surprising because this was seen in previous trials of SPAN (i.e., Narad et al., 2018; Wade et al., 2018) and because peer coaches have similar and socially relevant experiences to draw from and can provide a model for age-level social interaction (Bedell et al., 2017; Haarbauer-Krupa et al., 2010). In addition, two of the three participants and the parent who completed the 1-month follow-up indicated that they would have liked more sessions with coaches.

Many suggestions for improvement were received from the 1-week and 1-month follow-up surveys focused on the SPAN web app. Overall, the participant perceived certain aspects of the web app (i.e., the goal-setting function, breaking the goal into steps, and use of the strategies bank) as very useful and rated that they were very likely to continue to use those features. This result was reflected in the 1-month survey, where all four participants surveyed reported that they continued to use these features. However, the participants also reported barriers to accessing and reviewing the website on mobile platforms like tablets and smartphones. These results demonstrate the beneficial nature of the SPAN website and web app during and after the program and pinpoint areas of improvement to increase the usability of the web app, specifically focusing on optimization of the experience for use on smaller devices.

Overall, the participants rated the tips section of the website as both very useful and very likely to continue to use, while they rated the topics section as very useful but somewhat less likely to continue to use. When asked to further rate the individual tips and topics sections, all of the subjects were rated as very useful and very likely to continue to use. There are a variety of explanations for the tips being rated as somewhat more likely to be used than the topics after the program; however, the simplest explanations are that there were more tips than topics and that the tips were shorter in length than the topics. The shorter document length may have been more beneficial in the long term for the participants as compared to the longer topics because of the shortened timeline of this trial.

In addition to supporting the usability and feasibility of the program, these results provide preliminary evidence indicating the potential benefits of SPAN for promoting social participation and SPAN-related skills. Each participant achieved at least one goal and was working on other goals during and to be targeted afterward. These results suggest that although this was a briefer trial of SPAN, there still may be a somewhat longer-lasting impact through additional goal planning. In addition, most goals achieved during the 4 weeks focused on supporting existing social relationships, whereas many goals developed afterward focused on developing new social relationships. Shorter-term goals, such as getting together with a pre-existing friend, were mostly achieved in the 4 weeks, suggesting good potential for goals addressing newer areas, such as making a new friend, to be achieved in a longer period. However, this will need to be examined in future trials.

Scores in overall involvement in social participation increased with a medium effect size from pre to post program, reflecting a potentially positive impact on the nature of social participation. Scores in overall confidence in social participation also increased pre to post program with an approximately medium effect size, suggesting a potentially positive impact on the participants' feelings about their social participation. When broken down into areas of social participation, community and neighborhood participation scores had the largest increases with large effect sizes in both involvement and confidence, which reflects the areas targeted by the program as most goals focused on community engagement. School participation scores also showed increases in confidence with a large effect size and involvement with a small effect size. The difference in effect sizes for involvement and confidence was expected as the trial

occurred over the summer months when there were much fewer opportunities to engage in school-related activities. Unlike other areas that increased from pre to post trial, family and home scores decreased with a large effect size for involvement and medium effect size for confidence. This decrease may be because of the participants rating themselves as highly involved and confident prior to the SPAN program. Despite the decrease seen, home and family scores were still the highest-rated areas of involvement and confidence of all social participation scores. These high initial values may have left little room for improvement on the scale for the post program scores (i.e., potential ceiling effects). In addition, the goals developed by the participants mainly focused on areas outside the home, like work, school, developing friendships, and engaging in the community; the decrease in involvement may be because of the participants doing more activities outside the home.

Increases in confidence with essentially large to very large effect sizes were also seen for the scores for SPAN-specific skills from pre to post trial. These results are very promising as they imply that despite the briefness of the trial, this program might have supported increased confidence in fundamental skills to support future social participation. Developing the skills to self-manage within a circle of support is essential to the continuation of the principles and skills learned in SPAN given the short-term nature of the intervention (i.e., compared to the up to 10 coaching sessions provided in the full version of SPAN).

### **Limitations**

Although the findings of this study support the usability of the SPAN program for AYA brain tumor survivors, the results need to be considered with the limitations in mind. A key limitation of this study is the small sample size, which was sufficient to provide valuable usability information but not to make generalizable claims about the usability and effectiveness of SPAN in the wider population. Moreover, the SPAN measures used in this study were recently developed and require further psychometric study as more data were collected. Although the results of this study are promising, a larger implementation pilot trial of the full version of SPAN is necessary to examine its impact on social participation and other related skills. In addition, this study was held during the summer months, when adolescents and young adults who are still attending school often have more free time to engage in activities outside of schoolwork. Busy schedules due to school could be both a barrier and support for future SPAN implementation during the fall, winter, or spring months. Finally, this trial was completed in 2021 when the global COVID-19 pandemic and its restrictions were still in effect or beginning to loosen. Isolation and social distancing greatly impacted social participation, which may have contributed both to the success of this program (e.g., able to do remotely) as well as acted as a barrier to engaging in activities in the community or at school with others, as noted in the coach notes and open-ended survey responses.

### **Conclusion**

The results of this study are not generalizable but demonstrate the feasibility and usability of SPAN with AYA brain tumor survivors and provide preliminary evidence of the potential short-term benefits on social participation (at school and in the community) and related skills. The results have informed a larger pilot implementation study of the full version of SPAN (i.e., up to 10 weekly coach sessions) that involves further examination of the usability and potentially longer term benefits of SPAN for AYA brain tumor survivors. Although preliminary, the results contribute to an emerging evidence base related to social participation and virtual and app-based coaching and goal-planning interventions designed for adolescents and transition-age young adults with social and executive functioning challenges (O'Rourke et al., 2020). The results also align with evidence from existing participation-focused occupational therapy interventions that use person-centered strengths-based approaches to support goal achievement of children

and youth with a broader range of diagnoses and challenges (Anaby et al., 2022). The continued accumulation of promising evidence in these areas can potentially influence policy-level decisions that are advantageous to occupational therapy and related interdisciplinary fields (e.g., providing targeted resources and grant funding).

## References

- Anaby, D., Khetani, M., Piskur, B., van der Holst, M., Bedell, G., Schakel, F., de Kloet, A., Simeonsson, R., & Imms, C. (2022). Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice. *Disability and Rehabilitation*, *44*(9), 1746–1757. <https://doi.org/10.1080/09638288.2021.1903102>
- Anaby, D., Law, M., Hanna, S., & Dematteo, C. (2012). Predictors of change in participation rates following acquired brain injury: Results of a longitudinal study. *Developmental Medicine & Child Neurology*, *54*, 339–346. <https://doi.org/10.1186%2F13063-016-1357-6>
- Barakat, L. P., Hetzke, J. D., Foley, B., Carey, M. E., Gyato, K., & Phillips, P. C. (2003). Evaluation of a social skills training group intervention with children treated for brain tumors: A pilot study. *Journal of Pediatric Psychology*, *28*(5), 299–307. <https://doi.org/10.1093/jpepsy/jsg019>
- Barrera, M., & Schulte, F. (2009). A group social skills intervention program for survivors of childhood brain tumors. *Journal of Pediatric Psychology*, *34*(10), 1108–1118. <https://doi.org/10.1093/jpepsy/jsp018>
- Bedell, G. (2012). Measurement of social participation. In V. Anderson & M. H. Beauchamp (Eds.), *Developmental social neuroscience and childhood brain insult: Theory and practice*. (pp. 185–204). Guilford Press.
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y. C., Teplicky, R., Anaby, D., & Khetani, M. A. (2013). Community participation, supports and barriers of school-age children with and without disabilities. *Archives of Physical Medicine & Rehabilitation*, *94*, 315–323. <https://doi.org/10.1016/j.apmr.2012.09.024>
- Bedell, G., & Dumas, H. (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury*, *18*, 65–82. <http://doi.org/10.1080/0269905031000110517>
- Bedell, G., Wade, S. L., Turkstra, L. S., & Haarbauer-Krupa, J. & King, J. (2017). Informing design of an app-based coaching intervention to promote social participation of teenagers with traumatic brain injury: Stakeholder perspectives. *Developmental Neurorehabilitation*, *7*, 408–417. <https://doi.org/10.1080/17518423.2016.1237584>
- Carpentieri, S. C., Meyer, E. A., Delaney, B. L., Victoria, M. L., Gannon, B. K., Doyle, J. M., & Kieran, M. W. (2003). Psychosocial and behavioral functioning among pediatric brain tumor survivors. *Journal of Neuro-Oncology*, *63*, 279–287. <https://doi.org/10.1023%2FA%3A1024203323830>
- Chow, C., Liptak, C., Chordas, C., Manley, P., & Recklitis, C. (2018). Adolescent and young adult brain tumor survivors report increased anxiety even years after successful treatment for relapse. *Journal of Adolescent and Young Adult Oncology*, *8*(1), 90–93. <https://doi.org/10.1089/jayao.2018.0053>
- Gurney, J. G., Krull, K. R., Kadan-Lottick, N., Nicholson, H. S., Nathan, P. C., Zebrack, B., Tersak, J. M., & Ness, K. K. (2009). Social outcomes in the childhood cancer survivor study cohort. *Journal of Clinical Oncology*, *27*, 2390–2395. <https://doi.org/10.1200%2FJCO.2008.21.1458>
- Haarbauer-Krupa, J., Meulenbroek, P., Gibbs, J., & Turkstra, L. S. (2010). The BRAIN program: A model for transition to adult lives for teens with acquired brain injury. *Journal of Head Trauma and Rehabilitation*, *25*, 396–397.
- Hocking, M. C., McCurdy, M., Turner, E., Kazak, A. E., Noll, R. B., Phillips, P., & Barakat, L. P. (2015). Social competence in pediatric brain tumor survivors: Application of a model from social neuroscience and developmental psychology. *Pediatric Blood Cancer*, *62*(3), 375–384. <https://doi.org/10.1002/pbc.25300>
- Narad, M. E., Bedell, G., King, J. A., Johnson, J., Turkstra, L. S., Haarbauer-Krupa, J., Wade, S. L. (2018). Social participation and navigation (SPAN): Description and usability of app-based coaching intervention for adolescents with TBI. *Developmental Neurorehabilitation*, *21*, 439–448. <https://doi.org/10.1080/17518423.2017.1354092>
- O'Rourke, C., Linden, M., & Bedell, G. (2020). Scoping review of interventions to promote social participation in adolescents and young adults with neurodisability. *Open Journal of Occupational Therapy*, *8*(1), 1–22. <https://doi.org/10.15453/2168-6408.1647>
- Schulte, F., & Barrera, M. (2010). Social competence in childhood brain tumor survivors: a comprehensive review. *Support Care Cancer*, *18*, 1499–1513. <https://doi.org/10.1007/s00520-010-0963-1>
- Schulte, F., Vannatta, K., & Barrera, M. (2014). Social problem solving and social performance after a group social skills intervention for childhood brain tumor survivors. *Psycho-Oncology*, *23*(2), 183–189. <https://doi.org/10.1002/pon.3387>
- Ullrich, N.J., & Embry, L. (2012). Neurocognitive Dysfunction in Survivors of Childhood Brain Tumors. *Seminars in Pediatric Neurology*, *19*, 35–42. <https://doi.org/10.1016/j.spen.2012.02.014>
- Wade, S. L., Bedell, G., King, J. A., Jacquin, M., Turkstra, L. S., Haarbauer-Krupa, J., Johnson, J., Salloum, R., & Narad, M. E. (2018). Social participation and navigation (SPAN) program for adolescents with acquired brain injury: Pilot findings. *Rehabilitation Psychology*, *63*(3), 327–337. <http://doi.org/10.1037/rep0000187>
- Wade, S. L., Narad, M. E., Moscato, E. L., LeBlond, E. I., King, J. A., Raj, S. P., Platt, A., Thompson, A. N., Baum, K. T., & Salloum, R. A. (2019). Survivor's journey: Preliminary efficacy of an online problem-solving therapy for survivors of pediatric brain tumor. *Pediatric Blood & Cancer*, *67*(2), e28043. <https://doi.org/10.1002/pbc.28043>
- Wolfe, K. R., Walsh, K. S., Reynolds, N. C., Mitchell, F., Reddy, A. T., Paltin, I., & Madan-Swain, A. (2013). Executive functions and social skills in survivors of pediatric brain tumor. *Child Neuropsychology*, *19*(4), 370–384. <https://doi.org/10.1080/09297049.2012.669470>