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ORIGINAL ARTICLE



Informing design of an app-based coaching intervention to promote social participation of teenagers with traumatic brain injury

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ABSTRACT

Objective: To examine perspectives of multiple stakeholders to inform the design of an app-based coaching intervention to promote social participation in teenagers with traumatic brain injury (TBI). *Methods*: Teenagers and college students with and without TBI and parents of teenagers with TBI were recruited from two children's hospitals and two universities in the USA (*n* = 39). Data were collected via interviews, focus groups, and surveys and examined using descriptive statistics and content analyses. *Results*: Teenagers with TBI reported more social participation barriers and fewer strategies for addressing these barriers than teenagers without TBI. There was consensus across groups about the value of college student coaches and use of smartphones and apps. Participants expressed mixed views on the use of chat rooms and degree of parent involvement. *Conclusion*: Results provided insights about the possible benefits of the intervention, and informed its initial design (e.g., desired coach qualities, and type of coach training and supervision).

ARTICLE HISTORY

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KEYWORDS

Adolescents; rehabilitation; technology; tele-health; youth

Introduction

Social participation can be viewed as involvement or taking part in activities with others and is influenced by the interplay between the opportunities afforded by the environment and individual skills and knowledge needed for social functioning.^{1,2} Children and youth with traumatic brain injury (TBI) are at particular risk for long-term difficulties in social participation due to problems with foundational skills (e.g., social competence, executive functioning, physical functioning, speech, and communication) and environmental (social, attitudinal, and physical) barriers.^{3–7} Long-term follow-up studies suggest that difficulties with social functioning and participation after TBI persist into adulthood and contribute to poorer quality of life.^{8,9}

Social participation is particularly important for teenagers who are becoming more autonomous from parents and socially influenced by peers,^{10,11} and are learning new roles and skills that could assist them in adulthood.^{12–15} Teenagers with TBI and their parents frequently report social participation concerns such as social isolation, lack of meaningful friendships, and exclusion from social activities and opportunities.^{16–20} While children and youth with TBI and other acquired brain injuries (ABI) and their families do develop strategies to promote social participation, existing evidence suggests that they need greater support to find and create opportunities, educate others, modify activities, and obtain support and resources in school and community settings.^{17–20}

Despite evidence that social participation is critical for successful quality of life outcomes across the lifespan,¹²⁻¹⁵

evidence-based interventions to promote social participation for teenagers with TBI are lacking.²¹ Moreover, interventions designed to promote foundational skills such as problem-solving, self-regulation, and social communication in children and youth with TBI, while shown to have some beneficial effects on these specific skills, have not shown generalizable effects on social participation.^{22–28}

A review of the literature yielded only two studies of interventions specific to promoting social participation of teenagers with TBI²⁹ or ABI.³⁰ Glang and colleagues²⁹ tested the effectiveness of a school team-based problem-solving intervention to improving the social networks of three students with TBI. Each student was assigned a trained friendship facilitator (a special educator in the child's school), who supported the child in achieving individualized social participation goals. Participants had more social contacts and inclusion in activities with peers at the end of the intervention, but these changes were not maintained over time after the intervention was terminated. In a single case study on a teenager with ABI, Fraas and Bellerose³⁰ found improvements on measures of quality of life and participation after completing 10 weeks of weekly mentoring and activities at a communitybased program. Findings from these two studies are promising, but have limited generalizability given the very small sample sizes.

Teenagers with TBI often have difficulty applying knowledge to real-world settings,²⁸ difficulty evaluating solutions when problem-solving social situations, and often select developmentally immature strategies for solving social problems.³¹ Thus, evidence from intervention studies that focus on foundational skills, while not designed to improve social participation directly, might also have an impact on social participation and other aspects of social functioning.^{1,2} For example, evidence supports the use of metacognitive strategy and problem-solving training to improve behavioral outcomes following TBI in children and adolescents.^{22,23,26-} ^{28,32-34} Similarly, studies of online family problem-solving have documented improvements in parent-reported social competence with effects varying as a function of age and injury severity. Specifically, the problem-solving intervention was associated with greater increases in social competence, relative to an internet resource comparison, in younger teens with moderate injuries and in older teens with severe injuries.³³ However, none of these studies has directly examined the effects of these interventions on social participation. Taken together, these findings support the role of problemsolving skills as a necessary component of social participation while suggesting that problem-solving training alone may be insufficient to improve it directly.

In addition to the dearth of evidence-based interventions that address social participation and other aspects of social functioning, barriers to the delivery of these interventions abound. Outpatient services may be unavailable altogether or families may be forced to travel to obtain appropriate care. The delivery of a program through a tele-health medium addresses these barriers by increasing accessibility. Recent studies suggest that tele-health approaches provide an effective means of delivering interventions to adolescents with TBI and their families while reducing barriers such as time, distance, and available transportation.³⁵

To address the critical need for interventions to promote social participation of teens with TBI, the authors are conducting a three-year study to develop and test an app-based peer coaching intervention: Social Participation And Navigation (SPAN). The research presented in this article represents phase one of this larger 3-year study. A recent report from the Pew Internet and American Life Project³⁶ indicated that 73% of teens have or have access to a smartphone and are using apps, and virtual social networks at increasing rates, underscoring the potential utility of a smartphone app-based platform for SPAN. Moreover, smart phone apps for behavioral healthcare purposes have burgeoned in recent years, with apps for symptom monitoring, health education, skill development and practice, and connecting to resources.³⁷

The delivery of SPAN via smartphone apps might provide an effective means of delivering an intervention to adolescents with TBI and their families while reducing barriers such as time, distance, and available transportation.³⁵

We are developing the SPAN app and coaching intervention through an iterative design process. Iterative design is commonly used to design software and other technological devices and protocols³⁸ and incorporates some of the underlying principles and procedures of Participatory Action Research (PAR).^{39,40} The process involves solicitation of stakeholder feedback prior to building the app prototype and coach training and then continuing this process in multiple increments across all three project phases. The goal of each increment or iteration is to increasingly develop a more acceptable and usable system or product that can be shown to and then used by key stakeholders who then are able to provide more targeted feedback for application improvements and refinements. Participants (teenagers with TBI and their parents and college student coaches) in subsequent project phases will be able to provide ongoing formative and evaluative feedback while they are involved in feasibility (Phase 2) and open-label (Phase 3) trials.

The primary research team includes a clinical psychologist, an occupational therapist, two speech and language pathologists, and a software engineer/app developer. Our advisory committee includes parents of teenagers with TBI, young adults with TBI, and researchers and professionals working in special education and emerging adult community-based programs.

We envisioned a multi-pronged program integrating (1) a smartphone-based app to help teens identify, track, and implement social participation goals, together with (2) peer coaching to assist teenagers with problem-solving, strategy generation and scaffolding to achieve these goals, and (3) a companion website with didactic information about social participation, goal setting, problem-solving, and social communication. Our ideas were consistent with a top-down strengths-based approach focused on person-centered real-life social participation goals.^{6,17,25,28,41,42} This approach high-lights the teenager's strengths and supports while also addressing challenges and barriers that affect goal achievement rather than focusing on remediation of specific impairments or skill deficits (bottom-up).^{24,25,28,41,42} Our approach is consistent with principles of peer coaching.^{25,43–45}

Peer coaching is an intervention model in which peers serve as mentors for development and support of skills and knowledge in a particular domain, and is an ecologically valid approach to achieving generalization of skills often learned in therapy. Feedback from peers can be more powerful than comments from a therapist, who is likely to differ from the participant in socially relevant ways (e.g., age, interest, and social and educational experience).^{25, 34, 43-45} Peer coaches have the advantages of familiarity with smartphone technology, are less associated with stigma and can provide a model for age-appropriate social communication.⁴⁶ Moreover, results from a study that examined the effects of a college student peer-mediated metacognitive intervention designed for pre-adolescents with ABI demonstrated that pre-adolescents in the intervention group made greater gains than those in the control group on the measures of metacognitive strategy use and self-concept.34

We proposed that the peer coaches in SPAN would be undergraduate college students because they are typically close in age to teenagers, have graduated from high school, and navigated the transition to independence. Peers often exert greater influence on adolescent behavior than do parents or other adults, particularly in social interactions,^{10,11} and evidence suggests that generalizable benefits are most likely if intervention for individuals with TBI involves peers.-^{25,30,43-45}

The purpose of this Phase 1 study was to systematically examine the perspectives of multiple stakeholders to inform the initial design of the SPAN intervention. The primary objective was to obtain information about relevant content, feasible delivery methods, preferred approaches and strategies, and supports and barriers to promoting social participation.

Methods

Sampling and recruitment

This multi-site study conducted in the USA was approved by institutional review boards of all participating institutions (two children's hospitals and two universities). Convenience sampling was initially used to recruit participants and then purposive non-probability sampling⁴⁷ was used to try to obtain greater representation of viewpoints from participants from diverse backgrounds or who were underrepresented in our initial sample.

Teenagers with TBI and their parents were recruited from a large midwestern children's hospital where children received their TBI-related services. Teenagers with TBI met the following basic inclusion criteria: were between the ages of 14 and 19 and sustained injury at any point in their life either by blunt or non-blunt trauma. Exclusion criteria included: residence outside the home (e.g., a detention facility); pre-injury diagnosis of developmental cognitive impairment, severe developmental disability; developmental social disorder such as autism; or psychiatric hospitalization for the teenager or caregiver in the preceding 12 months. College students with TBI were recruited from one midwestern university and from among college students who had previously participated as coaches in a program for teenagers and young adults with TBI at a large southern children's hospital. College students without TBI were also recruited from this same group of coaches and from a northeastern university. Teenagers without TBI were recruited from faculty and research team contacts from this same northeastern university.

Data collection

Data were collected initially via survey (paper or electronic) and then by either focus group or interview. Surveys focused on preferred activities and participation frequency, barriers and facilitators to social participation, and mobile phone /app use. There were common questions asked of all stakeholders with slight variations dependent on the specific stakeholder group (see the appendix for a summary of these questions). Parents of teenagers with TBI were asked to report on what they thought their teenagers did and what they thought was most helpful for their teenagers.

Participants were then invited to participate in focus groups or interviews designed to gather broad-ranging feedback about social participation in teenagers and young adults with and without TBI and recommendations for the planned SPAN program, including: (1) current barriers and supports to participation; (2) thoughts about using college student coaches; (3) optimal levels of parent involvement; and (4) preferred content and procedures to consider for the SPAN app and intervention program.

All participants completed the surveys and participated in either a focus group or interview and were paid \$25 for their participation. Focus groups were approximately 90 minutes. Interviews took place at mutually agreeable locations or by phone or Skype and were 30–90 minutes depending on respondents' preferences and abilities. Field notes were written during and immediately after focus groups and interviews and described observations, impressions, key topics that emerged, and situations or other factors that might have affected the quality and quantity of responses.⁴⁸ All focus groups and interviews were audio recorded and transcribed verbatim.

We offered the choice of doing an interview or focus group to the teenagers with TBI and their families and college students with TBI based on what was convenient for them. We conducted five focus groups. The number of focus groups was determined by what was chosen by participants and what was possible given the time constraints for this phase of the larger project. Each group of stakeholders had a separate focus group. Teenagers with TBI, parents of these teenagers and college students with TBI each had one focus group. There were two additional focus groups conducted with college students who initially did not identify as having a TBI; however during the focus groups, one student identified that she had incurred a TBI as a teenager and two other students reported having a chronic health condition.

Phone or in-person interviews were conducted with all six teenagers without TBI, seven additional college students without TBI, and three college students with TBI. Interviews were conducted jointly with three teenagers with TBI and their parents. Interviews included the same questions that were asked in the focus groups, but the format was less structured given the greater amount of time and flexibility afforded. (See Table 1 for further breakdown of participants who were in interviews or focus groups.)

Data analyses

Descriptive statistics were computed on selected quantitative survey data. Content analyses were used to examine responses to open-ended survey questions and focus group and interview qualitative data from transcripts and field notes.^{47–50} The content analysis process involved recursive review of transcripts and field notes and then coding data by key topic, initially as topics pertained to each of the focus group or interview question and then across participant groups. Coded data were arranged by topics and subtopics using matrices, to facilitate review and comparison of topics across data sources and identify emerging patterns. Responses to the open-ended surveys across participant groups were integrated into the matrices when they pertained to each topic or subtopic. All data were then synthesized and winnowed down to

Table 1. Pa	rticipants iı	n	interviews	or	focus	groups	(n	=	39)
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Participant groups	Interviews	Focus groups	Total	
Teenagers with TBI	3	3	6	
Teenagers without TBI	6	0	6	
Parents of teenagers with TBI	3	4	7	
College students with TBI	3	3	6	
College students without TBI	7	7	14	
Total	22	17	39	

reflect the most relevant responses (from one or more participants). The results section includes a final distillation of these responses along with selected illustrative quotes.

Steps to ensure trustworthiness of the qualitative data, analyses, and findings included: (a) having at least two research team members review and cross check emerging findings, (b) discussing findings and analytic issues in twice-monthly team phone conferences, and (c) creating summaries of findings to review with team members and our advisory board that consisted of persons with or affected by TBI and interdisciplinary experts.^{47,50}

Results

Participants

This multi-site study had 39 participants from five participant pools (see Table 2): teenagers with TBI (n = 6) and their parents (n = 7), teenagers without TBI (n = 6), college students without TBI (n = 13), and college students with TBI (n = 7). The teenagers were between the ages of 14 and 19 years, and the college students were between 18 and 27 years. Most participants were White (75% teenagers, 86% parents, and 60% college students). Age of injury for teenagers with TBI ranged from 12 to 16 and number of years post-injury ranged from one to seven (mean = 3.8). Six of the seven teenagers with TBI had severe injuries (Glasgow Coma Scale [GCS] scores of 3 or 4) and one had a mild complicated injury (GCS score of 14).⁵¹ All teenagers with TBI were ambulatory and verbal, although additional sensorimotor consequences of the injury were noted in the three of the teenagers (i.e., vision issues for two teenagers and hemiparesis in one teenager).

Social participation barriers

Table 3 summarizes the key barriers described by teenagers with TBI and their parents and teenagers without TBI. Common barriers were related to time constraints, competing activities such as homework or extracurricular activities, and limited transportation to get to activities. Teenagers with TBI and their parents described many more barriers than did teenagers without TBI, and more often mentioned problems with balancing daily life activities.

Teenagers with TBI and their parents reported unique barriers to social participation, including feelings of isolation from peers, fatigue, behavioral challenges, not being able to drive (due to seizures or visual impairment), and lack of understanding from peers about effects of TBI.

Table 3. Summary of social participation barriers.

Teenagers without TBI

Limited time, opportunities, and transportation:

- ✓ Time constraints, due to school and other extracurricular activities
- ✓ Harder to participate in competitive sports and recreational activities when you are older (easier when you are younger)
- ✓ Limited availability of activities just for fun
- \checkmark Limited transportation to get to activities

Social challenges

- ✓ Need for a companion to explore new activities—solo exploration can be difficult
- ✓ Intimidation—especially when joining activities with older or more experienced participants

Teenagers with TBI

Peer challenges

- ✓ Friends are present in the beginning, but then dissipate
- ✓ Lack of understanding and empathy from peers
- ✓ Talking with or educating peers is exhausting; teenager will give up on explaining their limitations to peers
- ✓ People treat teenager differently, and in turn, teenager becomes irritated and self- isolates
- ✓ Withdrawal from previous activities is misunderstood—peers can interpret this as rejection
- ✓ Declined invitations can result in lack of future invites

✓ Some teenagers are mean

Social and behavioral challenges

- ✓ Difficulty initiating social contact and joining conversations (due to not having a sense of humor and difficulty discussing common interests)
- ✓ Lack of initiative—initially thinking they do not want to participate and then feeling that they are missing out
- ✓ Becoming more introverted
- \checkmark Behavioral challenges, such as being too blunt or laughing too long or too loud

Other TBI-specific challenges

- ✓ Parent or medical restrictions on activities
- Physical limitations
- \checkmark Issues with sleep—often feeling tired or fatigued
- ✓ Poor memory for events
- ✓ Difficulty setting goals on their own
- \checkmark School workload—difficult to find a work/fun balance
- \checkmark Not being able to drive (teens with seizures or visual impairments)

They don't understand that we change, and usually for the better. Right after my injury, I was kind of standoffish and not really wanting to do anything with my friends, but now I try to initiate stuff and it's more difficult because they're like "Wait, I thought you were the one who didn't want to hang out". (Teenager with TBI)

Teenagers without TBI identified challenges such as being intimidated when joining or trying new activities, and limited availability of activities that can be done just for fun or on a less structured basis.

Social participation supports and strategies

Teens without TBI were more likely than those with TBI to report strategies for facilitating social participation, although

Table 2. Demographics.			
	Teenagers $(n = 12)$	Parents of teenagers with TBI $(n = 7)$	College students ($n = 20$)
TBI status	TBI (<i>n</i> = 6; 50%) No TBI (<i>n</i> = 6; 50%)	No TBI (<i>n</i> = 7; 100%)	No TBI (<i>n</i> = 13; 65%) TBI (<i>n</i> = 7; 35%)
Sex	Male $(n = 7; 58\%)$ Female $(n = 5; 42\%)$	Female ($n = 5$; 71%) Male ($n = 2$; 29%)	Male $(n = 6; 30\%)$ Female $(n = 14; 70\%)$
Age range Race and ethnicity	14–19 years White $(n = 9; 75\%)$ Black $(n = 1; 8\%)$ Hispanic $(n = 1; 8\%)$; Mixed Race $(n = 1; 8\%)$	46–54 years White ($n = 6$; 86%) Black ($n = 1$; 14%)	18–27 years White $(n = 12; 60\%)$ Asian $(n = 5; 25\%)$ Black $(n = 1; 5\%)$ Hispanic $(n = 1; 5\%)$ Mixed Bace $(n = 1; 5\%)$

both groups used strategies such as checking weekly activities or events, and signing up for and joining clubs and other activities. Teenagers without TBI also described a broader range of strategies, including scheduling things ahead of time, using daily or weekly planners, practicing skills needed to participate, asking peers and adults (parents, teachers, coaches) for help and earning money to afford preferred activities, altering expectations of oneself, and asking a friend to join in for making participation in new or competitive activities more fun. Teenagers with TBI also identified strategies and activities that promote participation such as hanging out with friends at school, talking or texting friends on a regular basis, doing volunteer work and asking friends to do preferred activities with them.

When asked about what others could do to promote teenagers' social participation, some teenagers with and without TBI described the need for the involvement of others, such as parents, to create opportunities and social gatherings and to be offered rides to attend activities. Teenagers without TBI also mentioned that it would be helpful if parents paid for activities and if parents or others would remind them about activities and participate with them. Parents of teenagers with TBI said they reached out to peers and teachers to engage their teenagers, and explored on-line organizations and community as well as church groups for social opportunities. Two parents also stated that social media supported social participation of their teenagers.

Feedback informing the design of SPAN

SPAN should be able to fit the needs of each teenager. It should not try to change the teenager, but rather to encourage interaction. (Parent of teenager with TBI)

Feedback from teenagers, parents, and colleges students focused on four key topics: (1) interacting with college student coaches; (2) using and interacting with smart phones and apps; (3) use of chat rooms; and (4) parent involvement. Table 4 summarizes participants' comments.

College student coaching

Having someone I trust to say, "How do you think people perceived that?" could be good for when mistakes are made and you know you're isolated as a result. You need to express yourself and learn from your mistakes. (Teenager with TBI)

Overall, participants agreed on the value of having college student coaches interact with teenagers with TBI. Participants described the coach as a figurative "partner in crime" and "confidant," and emphasized coach traits and skills such as being kind, positive, a good listener and communicator, and able to encourage and help teenagers to identify goals, problem solve, and generate strategies to achieve goals.

Smartphone and app use

There was consensus about the value of using and interacting with smartphones and apps, and using FaceTime[®] or SkypeTM. Most participants described the importance of staying connected and having access to updated information. Many reported that interacting by phone might make teens more comfortable than in-person conversation, and would allow

teenagers to remain in their natural settings rather than having to go to a clinical setting.

All teenagers with TBI had excellent or above average knowledge and skills related to smartphone and mobile apps, according to both the teenagers and their parents. Parents identified that their teenagers often helped them use their smartphones and download apps. Of interest, teenagers with TBI, on average, reported higher knowledge, skills and smartphone usage than teenagers without TBI.

All teenagers and college students with TBI had smartphones. Three of the six teenagers without TBI and 9 of the 13 college students had smartphones. Those who did not have smartphones attributed it to cost or lack of need or desire to own one. All but one of the college students identified that the iPhone^{*} was their preferred smartphone of choice.

Parents either agreed or strongly agreed with the statement that "smartphones were important in daily life", as did most teenagers and college students with TBI. Participants without TBI had more varied responses (i.e., disagree to strongly agree). One teenager without TBI remarked that she thought "teenagers would be comfortable with smartphones, but that this should not be mistaken for a preference for phone communication over in-person interaction". A few college students without TBI indicated that smartphones were overvalued and that resources could easily be accessed elsewhere or in other ways.

Chat rooms

We could say "hey, this is the problem I had today. You might be able to relate to it." (College student with TBI)

All six teenagers with TBI, three of the six teenagers without TBI, and most of the college students used social media sites. Facebook was identified most frequently followed by Twitter and Instagram. There were a number of positive responses to chat rooms across all stakeholder groups, such as being a good way for teenagers to get feedback from other teens and coaches and that chat room interaction is one form of social participation. Some participants thought it would be important to limit the number of chat room members because of "the need to feel you know people for social reinforcement to be effective".

College students with and without TBI had the most comments about chat room format, expressing that there should be a range of chat rooms geared to different groups of participants or based on interests. College students without TBI also thought that a separate coaching chat room would be good to get support and feedback from others and share coaching tips. Confidentiality and safety concerns, such as sharing inappropriately or with ill intentions (e.g., cyber-bullying), were mentioned by college students and parents of teenagers with TBI. Some of the college students without TBI indicated that the chat room should be restricted to SPAN participants and not be open to the public.

Parent involvement

I would be all for letting him be in control of it. I very much want to see him learn self-advocacy skills. (Parent of teenager with TBI)

Overall, there was consensus across participants that the ultimate aim was to have the teenager with TBI become as autonomous as possible and use family and friends as

Table 4. Summary of feedback informing the design of SPAN.

College student coaching

Benefits:

- \checkmark College students are relatable
- \checkmark Value in having a confidant; someone to talk to and vent frustrations; might alleviate social isolation
- \checkmark Could provide opportunity to discuss appropriate social behaviors in advance of events
- ✓ Young people and college students feel more real; better able to understand and have better chance of reaching teenager
- \checkmark College students can be very available via mobile phones

Concerns

- \checkmark Should <u>not</u> try to change the teenager, but rather to encourage interaction.
- \checkmark Need to remember that teenagers do not want to be defined by their brain injury
- \checkmark Make sure coach understands that dropping out would be detrimental to teenager
- ✓ Coaches might not be able to relate to teenager because of age gap or because they have not had a TBI
- ✓ Coaches must have adequate training
- Recommendations:
- \checkmark Coaches will need to be understanding, good listeners, patient, kind, positive, and available
- \checkmark Match coaches and teens based on shared interests or gender identity
- \checkmark Should be able to adapt to teenager's individual needs and preferences for how to receive help
- ✓ Must have strong communication skills—especially virtually
- ✓ Must be able to help teenager set goals, solve problems and generate strategies (areas where teenagers with TBI have challenges), and offer suggestions
- \checkmark The relationship should be professional and purposeful
- \checkmark Will need to set clear boundaries and guidelines for discussion content and type of relationship
- Range in responses for type and amount of contact between teenagers and coaches (as needed, daily to weekly; 15 minutes to 45 minutes sessions; combination of phone and text)

Smartphone and app use

Benefits:

- ✓ Face time/SkypeTM could be useful for facilitating social interaction especially if there is no in-person contact
- ✓ Phone conversations may make teens more comfortable than face to face in person conversation
- ✓ Less stigmatizing than attending clinical appointments (due to the ubiquitous nature of smart phones and apps)
- ✓ Capitalizes on smartphone and app proficiency of teenagers with TBI

Concerns:

- ✓ Building relationships through apps could be difficult
- \checkmark Need to have a clear idea of what you want the app to do
- ✓ Teenagers feel comfortable with technology but this should not be mistaken for preference

Recommendations:

- ✓ Customize the app to make it more meaningful to teenagers
- ✓ Profile pages for the teen and coach will help the teenager and coach get to know each other
- ✓ Should help teenagers with goal setting and planning because this is challenging for them
- ✓ Should be easy step-by-step process with clear directions
- ✓ An interactive app with reminders is preferable
- ✓ Keeping focus of the app narrow to allow for higher quality versus having too many functions
- ✓ Multi-platform is key (smartphone, tablet, computer), especially since motor coordination and vision could be challenging on small devices and screens

Chat rooms

Benefits:

- ✓ Provides sense of community
- ✓ Virtual social engagement is appealing, especially when in-person engagement is difficult
- ✓ Good opportunity for teenagers to get feedback from peers and other coaches or mentors
- \checkmark Strength of virtual community is to provide a social outlet
- ✓ The chat room alone might fulfill a goal of being social

Concerns:

- ✓ Chat rooms might allow for sharing information inappropriately or with ill intent; cyber-bullying
- ✓ Concern about confidentiality and anonymity
- ✓ Concern about just having teenagers with TBI interact solely with teenagers with TBI (i.e., the ultimate goal is to socially integrate in natural daily contexts in spite of TBI)

Recommendations:

- ✓ Should provide different chat room options with restricted access: Full group or subgroups (e.g., teens only; coaches only; organized by interests)
- \checkmark Chat room should be specific to intervention and not open to the public
- ✓ Number of participants should be limited ("you need to feel you know the people for social reinforcement to be effective" ~teenager without TBI)
- ✓ Make sure teenagers get prompt feedback to their questions

Parent involvement

Benefits

- ✓ Involvement would allow parents to anticipate changes (good or bad) and provide additional scaffolding to help teen accomplish goals
- \checkmark Younger teens would be more interested in having parents involved
- \checkmark More parent involvement might be needed if teenager has more challenges

Concerns

- ✓ Opportunity for teenagers to exercise autonomy, so too much parent involvement could limit the impact of intervention
- ✓ Involvement might get in the way of the teenager—coach relationship
- ✓ Involvement in goal planning might increase pressure on teen to perform

Recommendations:

- ✓ Degree of involvement should be dictated by teen's comfort level and needs
- ✓ Provide way for parents to get answers to questions (e.g., direct connection to coach supervisor)
- ✓ Offer to provide progress reports to parents
- ✓ Minimal involvement to view progress and to know what teenager is working on and to see teenager and coach profile with varying degrees of access rights
- Y Provide additional background information to coach about teenager (e.g., teenager's needs, activities, how teenager likes to be helped, effective strategies)

scaffolding to support and reinforce social participation goals. Most college students emphasized the importance of having a trusting relationship with the teenager and thought that only minimal involvement with parents was needed. While teenagers with TBI expressed mixed views about parent involvement, their parents felt that their input would be important to provide a clearer sense of the teenager's actual level of participation and the nature of social participation barriers. Several parents noted that their teenager downplayed barriers or were sometimes unaware of their challenges.

Participants across stakeholder groups thought that the level of parent involvement should correspond with the teenager's comfort level, age, and preferences, and that the level of involvement might change over time as needed. Some of the parents and college students suggested that parent involvement might include initial introductions, some kind of web or app access to review the teenager's goals and plans during the intervention, and information about the teenager's progress during or at the end of the intervention.

Discussion

The results provided important information to guide development of the SPAN app and intervention protocol. There was consensus across groups regarding the potential value of smartphones and an app to promote social participation and the utility of college student coaches. Many participants highlighted the importance of tailoring the program or intervention to the needs and preferences of the teenagers which is consistent with a person-centered approach.^{52,53}

Social participation barriers, supports, and strategies

Teenagers with and without TBI both reported challenges around finding time for social activities. However, teenagers with TBI experienced a number of additional barriers associated with their injury that further impeded participation, and also identified fewer strategies for dealing with these barriers. These findings are consistent with the problem-solving literature which suggests that adolescents with TBI generate fewer solutions to problem scenarios.³¹ Teenagers with TBI identified social and behavioral changes that interfered with participation such as lack of initiation, increased introversion, and difficulty regulating social behaviors, as well as perceptions that peers were unwelcoming and less willing to engage with them after the TBI. Participants also noted physical issues such as fatigue, sleep problems, and the inability to drive due to seizures or visual impairments. Therefore, peer coaches will need to be cognizant of these TBI-specific issues, and the intervention must include strategies for working around them.

In our study, teenagers and college students without TBI identified a broader range of strategies for promoting social participation than did teenagers with TBI. In particular, teenagers without TBI were more likely to look for participation opportunities in advance, stay connected with friends regarding opportunities, and make sure to schedule things in advance. Given the social isolation and cognitive impairments of many teenagers with TBI, strategies such as planning ahead with friends may not be feasible without additional structure or support. Engagement with peers may also require challenging perceptions that peers are "mean" or that existing friends have moved on, factors that did not affect participation among the teenagers without TBI.

The design of SPAN must consider principles from evidence-based interventions that have demonstrated some success in supporting goal setting and planning, self-regulation, social communication, and problem-solving of teenagers with TBI.^{22-24,26-28} However, because these interventions have not consistently shown generalizable effects on social participation, SPAN also will need to incorporate intervention principles and effective strategies known to promote social participation including supports for planning and preparing ahead of time; acquiring or practicing skills needed to participate; modifying cognitive, psychosocial and physical demands of the environment; and leveraging family and community resources.^{17,29,30,41,54} These intervention strategies and principles are consistent with a top-down strengths-based approach that focuses on achievement of person-centered social participation goals rather than a bottom-up remedial deficit-based approach.6,17,25,28,41,42

College student coaching

All stakeholders were enthusiastic about the use of college student coaches to deliver the program and help set participation goals with the teenager. Although there is no strong evidence supporting any one coaching method or model, there is a considerable and growing literature suggesting that peer mentors and coaches can effectively help adolescents develop and work on goals and solve problems, and provide emotional support.^{30,34, 43–45,55–59}

Many of the desirable coach characteristics and skills identified by participants in this study have been described in the youth mentoring and peer mentoring literature, such as having excellent communication and listening skills and being able to support the adolescent. Key to the effectiveness of mentor-youth relationships is a sense of mutual trust and that the youth feels understood, liked, and respected.⁵⁹ Thus, these coach traits and skills will need to be reinforced in our coach training and supervision.

Smartphone and app use

Data from the Pew Research Center's Internet and American Life Project³⁶ support our finding that teens with TBI are proficient and enthusiastic smartphone users. The Pew study found that smartphone adoption among American teenagers, ages 13–17, has increased substantially over the past decade. From a nationally representative sample of over 1060 teenagers, 73% reported that they have or have access to a smartphone. A very high proportion (91%) of the teenagers endorsed accessing the internet on mobile devices, suggesting a mobile application would be accessible and acceptable to most teenagers. A few teens in our study also suggested using a tablet or computer rather than a smartphone, given the better visibility of larger screens and greater ease in typing.

Although our sample was limited, our teenagers with TBI had higher smartphone usage and endorsed higher levels of proficiency with the device than did teenagers without TBI. The results suggest that teenagers with TBI may already be relying on smartphones as cognitive prostheses and may be particularly receptive to app-based interventions.

Chat rooms

Participants in this study identified both benefits and risks of social media sites or chat rooms. Similar risks have been reported in the literature on social media use by adolescents,-^{60–62} including cyber-bullying, disclosing of inappropriate personal information, exposure to sexual predators, distraction from school work, and avoidance of in-person social activity. Previous studies^{60–62} also identified social media benefits similar to those reported by our participants, such as being a place to seek emotional support, connect with and make friends, develop a personal and social identity, and obtain information about social events and diagnosis-specific resources.

The recent Pew report³⁶ identified that the Facebook was the social media site used most frequently by teenagers (41%). This finding is consistent with the reports of teenagers and college students in our study and with findings from other researchers.^{60,61,63} However, participants in our study also recommended that we develop our own SPAN-specific social chat room to avoid many of the previously described social media use risks. Thus, we will need to solicit additional feedback to inform what kind of social chat room, if any, to develop for SPAN, while considering the reported risks and benefits and the additional resources needed to develop and manage the site.

Parent involvement

There were diverse opinions expressed across participant groups about the type and extent of parent involvement, from no involvement to full involvement. Overall, the findings were consistent with the view that the primary focus should be on the development and ultimate benefits of the mentor-youth relationship with parents and professionals playing a supportive role.⁵⁷⁻⁵⁹ All stakeholder groups recognized that each teenager's developmental stage and degree and nature of impairments should be taken into consideration when determining the level of parental involvement, suggesting that parent involvement will need to be individualized. We also will need to address parents' concerns about their teenager's lack of awareness and coaches not having the most accurate information about the teenager.³⁰ Given this feedback, it will be important to find a balance between promoting teenager autonomy and an exclusive relationship between the teenager and coach and allowing for parental input and scaffolding.

Conclusions

The results provide support for the development of the SPAN app and coaching intervention and are consistent with themes from the literature. The results suggest that SPAN should use a structured approach that is tailored to the individual needs, preferences, and social participation goals of teenagers.

The study had limitations as well. Data were collected from a small group of participants from settings and/or people with which the team was familiar. Thus, while our results were applicable and informative for our purposes they are potentially biased and not generalizable to the broader population.

Due to time constraints and lack of prolonged engagement with participants in this phase of the study, we could only provide a summary of participants' common and unique responses to our survey and interview/focus group questions. Additionally, we could only report general trends to highlight some of the differences between teenagers with and without TBI because our qualitative data came from different data sources (teenagers with TBI and their parents, teenagers without TBI) and different data collection methods (focus groups, interviews, open-ended survey questions). Finally, we were unable to collect other relevant feedback in this phase of the study such as where coaches and teenagers could interact and teenagers could use the app (e.g., home, school), whether and how to involve others (e.g., peers, professionals, paraprofessionals), what specific content and strategies that teenagers and parents and coaches would want to include, and how to monitor progress and assess outcomes in SPAN.

Our methods served our primary goal of confirming and expanding our existing conceptualization of SPAN and the future work that would need to be considered. Thus, consistent with our iterative design process,³⁸ we will be collecting additional feedback from our advisory board and other stakeholders to address the issues raised by participants in this phase of the larger project (e.g., type of parent involvement and social chat room), and to obtain their expertise to guide the design and development of SPAN. We also will be obtaining more targeted action-oriented feedback from the teenagers with TBI, parents, and college student coaches who will participate in our subsequent feasibility and open-label trials.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Appendix: *Common survey questions asked of teenagers, college students, and parents

I Social participation

- (1) What is your favorite social activity (an activity that you like to do with friends or others from your community or school)?
- (2) How often do you typically do this social activity? (Daily to Once Yearly)
- (3) How would you describe the opportunities for participating in social activities in your community and school? (Poor to Excellent)
- (4) What kinds of things interfere with your ability to participate in social activities in your community and school?
- (5) What kinds of things do you do to be able to participate in social activities in your community and school?
- (6) What do others do to help you participate in social activities in your community and at school?

II Cellphone /app use

- (1) Do you own a mobile phone? (Is it a smartphone?)
- (2) What is the model of your mobile phone?
- (3) Please list phones/models you have experience with:
- (4) How old were you when you received your first mobile phone? (your first smartphone?)
- (5) Approximately, how many texts do you send a day?
- (6) Do you use any other features of your mobile phone (or smartphone)?
- (7) If so, how much time do you spend on them a day?(A list was provided; Don't use it to Greater than 5 hours)
- (8) How often do you use the following types of apps on a typical day? (A list was provided; Don't use it to Greater than 5 hours)
- (9) Using a mobile phone or smartphone is a very important part of life (Strongly agree to Strongly disagree). Briefly explain:
- (10) I would rate my mobile phone or smartphone abilities as (Poor to Excellent). Briefly explain:
- (11) Please describe up to three features of a mobile phone or smartphone that you like the best or find most helpful to you. Briefly explain:
- (12) Please describe up to three features of a mobile phone or smartphone that you don't like or find unhelpful to you. Briefly explain:
- (13) What type of smartphone would you want if you could afford it? Briefly explain:
- (14) Please name or describe up to three apps that you like the best or find the most helpful to you. Briefly explain:

*There were slight variations in surveys specific to each stakeholder group. Parents of teenagers with TBI were asked to report on what they thought their teenagers did and what they thought was most helpful for their teenagers.