Social Participation And Navigation (SPAN) for Teens with TBI: Phase 1 development of an app-based coaching intervention

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Background

- Teens with traumatic brain injury (TBI) often experience limitations in their social participation within school and community activities.[1-3]

- Social participation is associated with enhanced quality of life and is a primary rehabilitation outcome.[1,2,4-7]

- Despite evidence that social participation is critical for successful outcomes, evidence-based interventions to promote social participation for teens with TBI are lacking.[8]

- Teens with TBI and their parents underscore concerns with social isolation, lack of meaningful friendships, and exclusion from social activities and opportunities.[9-13]

- The ultimate aim of this three phase study is to develop an intervention, Social Participation and Navigation (SPAN), to promote social participation among teens with TBI via smart phones, a mobile app, college student coaches and linkages to a virtual community.

- SPAN will be designed to support teens with TBI developing and achieving social participation goals with assistance from coaches, a mobile app, strategies and information resources.

Purpose

The purpose of Phase I of this study was to systematically examine the perspectives of stakeholders in order to inform the SPAN design and functionality.

The three research aims were to:
1. Increase understanding of factors influencing social participation among teens with TBI
2. Identify preferred approaches for facilitating and supporting social participation
3. Describe perspectives about feasibility and key features to consider for SPAN: Use of smart phones, mobile apps, college student coaches, and strategies and resources to support social participation goals

Key Methods

- This multi-site study had 4 participant pools: college students mainly without TBI (Tufts, n=7 and Children's Health Care of Atlanta, n=9), college students with TBI (University of Wisconsin-Madison, n=4), teenagers without TBI (Tufts, n= 6), and teens with TBI and their parents (Cincinnati Children's Hospital, teens, n=6; parents; n=7).
- Data were collected via survey, interviews and focus groups.
- Surveys were developed to collect data on technology use, preferred activities and participation frequency, as well as barriers and facilitators to participation.
- Interview and focus group guides focused on barriers and supports to participation, views about college student coaching and key content and features for SPAN.
- Content analyses were used to organize data (from interviews, focus groups and open-ended survey questions) into key content categories and responses.

Results

Table 1: Demographics

	College Student Demographics (n=20)	Teenager Demographics (n=12)
Gender	Male 30% (6); Female 70% (14)	Male 58% (7); Female 42% (5)
Age range	18 – 20 years old 40% (8); 22 – 24 years old 45% (9); 25 – 27 years old 15% (3)	14 – 16 years old 67% (8) 17 –19 years old 33% (4)
Race & Ethnicity	White 60% (12); Black 5% (1); Asian 25% (5); Latino 5% (1); Mixed Race 5% (1)	White 75% (9); Black 8% (1); Latino/ Hispanic 8% (1); Mixed Race 8% (1)
TBI Status	No TBI 70% (14) History of TBI 30% (6)	No TBI 50% (6) History of TBI 50% (6)

Table 2: Social Participation Barriers

|	Key Responses	Illustrative Quotes
Teens without TBI	✓ Need to start young in order to participate in competitive sports/recreational activities ✓ Limited availability of activities just for fun ✓ Time constraints, due to school and other extra curricular activities ✓ Need for a companion to explore new activities– solo exploration can be difficult ✓ Intimidation – especially when joining activities with older or more experienced participants	*"If there were a less intense option or a place to play 'just for fun', that would probably help.* *Also, lack of regularity would be good, or not an expectation to be there every week for the game if you have a bunch of other work to do."*
Teens with TBI	✓ Lack of understanding and empathy from peers ✓ Talking with or educating peers is exhausting ✓ People treat teen differently post TBI; in turn, teen becomes irritated and self-isolates ✓ Withdrawal from previous activities is misunderstood – interpreted as rejection of peers ✓ Not being able to drive (teens with seizures or visual impairments) ✓ School workload – difficult to find a work/fun balance ✓ Behavioral challenges, such as being too blunt or laughing too long/ too loud ✓ Being more introverted ✓ Lack of initiative – thinking they don't want to participate and then feeling that they are missing out ✓ Declined invitations can result in lack of future invites ✓ Difficulty initiating social contact ✓ Issues with sleep – often feeling tired or fatigued ✓ Poor memory for events	*"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."*

Table 3: SPAN Phase 1 Feedback

Categories	Key Responses	Illustrative Quotes
Positive feedback & concerns	✓ College students are relatable – they ✓ will need to be understanding, good listeners, positive, and available ✓ Desirable opportunity for college students – a "partner in crime" ✓ Value in having a confidant ✓ Teens might lack awareness of specific problems that impact social participation ✓ Chat rooms might allow for sharing information inappropriately or with ill intent; cyber-bullying	*"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**
Phones & apps	✓ Set clear boundaries and guidelines for relationship ✓ Use Face time/Skype for facilitating initial connection ✓ Phone conversations may make teens more comfortable than face to face conversation ✓ Customize the app to make it more meaningful to teenagers ✓ Profile pages will help the teenager and coach form a relationship ✓ An interactive app with reminders is preferable	*"Using phones makes sense as a way to connect people. It's far easier than being face to face."* **~ Teenager without TBI**
Chat rooms	✓ Provide sense of community ✓ Virtual social engagement is appealing, especially when in-person engagement is difficult ✓ Good opportunity for teens to get feedback from peers and other mentors ✓ Provide options: Full group or subgroups (e.g., teens only; mentors only; by interests); ✓ Need to consider anonymity	*"If it were anonymous, we could say 'hey, this is the problem I had today'. You might be able to relate to it."* **~ College student with TBI**
Training content & Supervision	✓ Resources to references as needed ✓ Typical challenges of teens with TBI ✓ Expectations for interaction ✓ How to engage in conversation ✓ How to motivate towards goals ✓ Guidelines for termination ✓ When to notify supervisor about safety concerns and what to do in case of emergencies ✓ College students wanted weekly supervision and teen background (specific challenges, interests, tips)	*"Structured training at the beginning would be helpful because it's important for the mentors to know how to engage the kids, how to remain sensitive to certain things."* **~College student without TBI**
Parent involvement	✓ Degree of involvement should be dictated by teen's comfort level ✓ Younger teens more interested in having parents involved ✓ Opportunity to exercise autonomy -- too much parent involvement could limit impact of intervention ✓ Offer to provide progress reports ✓ View progress and see profile with varying degrees of access	*"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**

Discussion

- The teens with TBI experienced feelings of isolation from peers, fatigue, behavioral challenges, life balance difficulties, seizures, visual impairment and a lack of understanding from peers about the effects of TBI.

- Consequently, teens with TBI experienced unique barriers to social participation.

- Teens and college students without disabilities were more likely to report systematic strategies for facilitating social participation, such as scheduling things ahead, checking lists of weekly activities, and joining clubs.

- There was consensus about the value of having college students help promote teens' social participation.

- Results gave insights into ideal qualities of prospective coaches (e.g. availability, interpersonal skills), the degree to which parents should be involved, the pros and cons of having a social chat room, and the type of training and supervision needed for college students.

- Results informed Phase 2 of the larger study that involved initial development of SPAN and design of the prototype app →

- Usability and pilot testing is underway to examine feasibility and obtain feedback to inform further revisions.

- Teens with TBI have been paired with college student coaches from two universities to help teens use the SPAN app and web-based resources to identify, create and implement plans to achieve social participation goals.
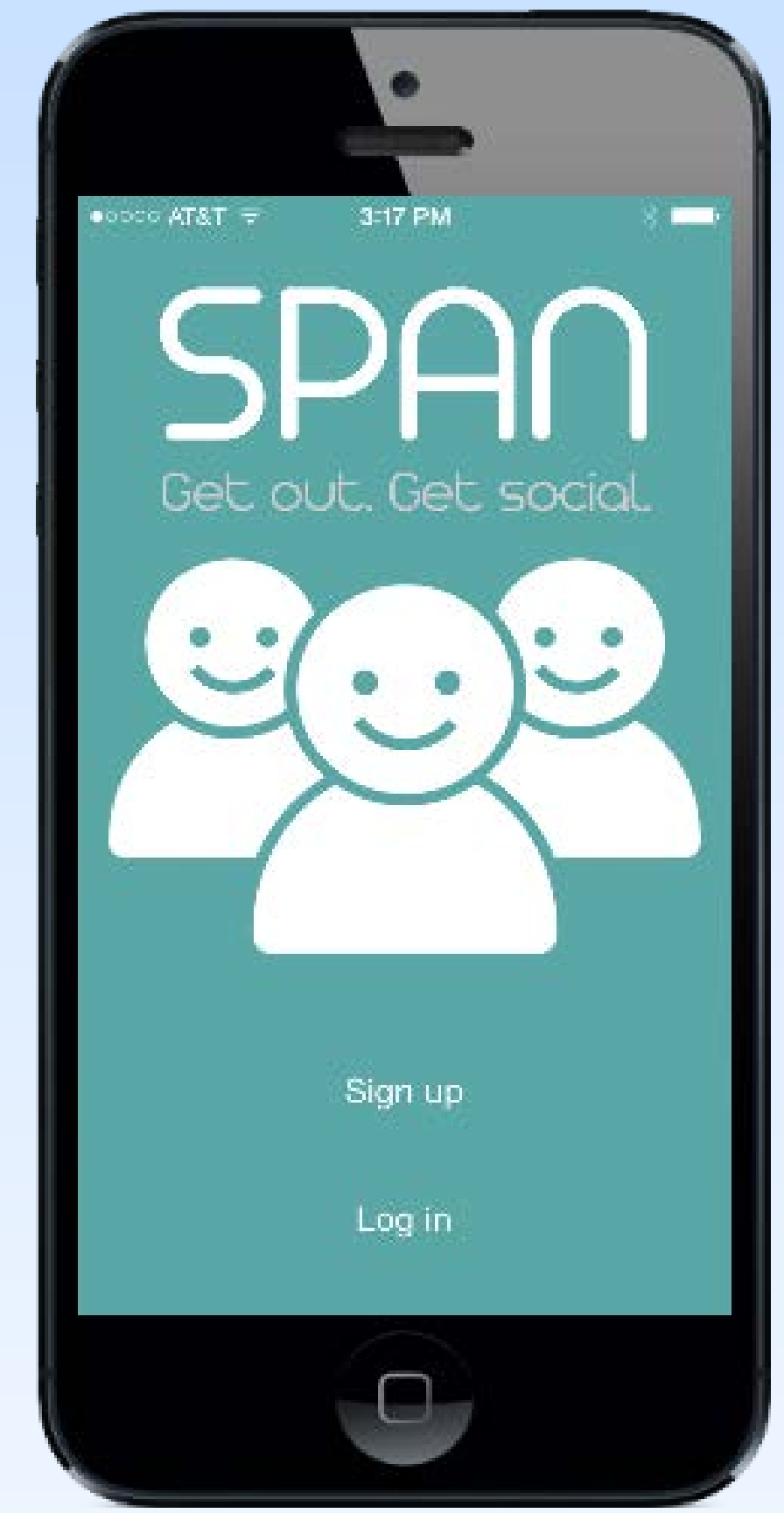
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