

Social Participation And Navigation (SPAN): Intervention pilot for teenagers with Acquired Brain Injuries (ABI)

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 - **The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS.**

Multi-site & interdisciplinary study

Collaborators

- **Tufts University:** Gary Bedell, Co-PI, Michele Jacquin
- **Cincinnati Children's Hospital Medical Center:** Shari Wade, Co-PI, Megan Narad, Jessica King
- **University of Wisconsin-Madison/McMaster University:** Lyn Turkstra, Co-I
- **Georgia Institute of Technology:** Jeremy Johnson
- **Children's Healthcare of Atlanta:** Juliet Haarbauer-Krupa

Objectives

- Briefly describe **SPAN: An app-based coaching intervention**
- Report on 10 week implementation pilot with 13 teens with TBI & brain tumors (BT)

Person-centered iterative design

- **Phase 1: Stakeholder focus groups & interviews to inform design** (Bedell, et al., 2016)
 - Developing first prototype of SPAN and app
 - Advisory board feedback
- **Phase 2: Usability test with 4 teens with TBI paired with 4 college student coaches** (Narad, et al., 2017)
 - Developing 2nd prototype of SPAN program and app
 - Advisory board feedback
- **Phase 3: Current study: Briefly presented today** (Wade, et al., 2017)

Social Participation

- Often used interchangeably with “Participation” (defined broadly as ‘involvement in life situations’) (WHO, 2007)
- Taking part, involvement, engagement, doing or being with others (Bedell, 2012)
- Involvement in activities that provide interactions with others in society or the community (Levasseur, et al., 2010).
- Levasseur, et al. proposed a six level hierarchical taxonomy of social activities (3-6 reflect social participation)
 1. Activities in preparation for connecting with others
 2. Being alone with others around
 3. Interacting with others without engaging in a specific activity
 4. Collaborative activities
 5. Helping others
 6. Contributing to society

SPAN: Content & procedures

- 1. iPhone app to support goal setting, planning & implementation**
 - Teen / coach profiles (linked in app)
 - Push notifications for reminding / reinforcing
- 2. Online Key Topics and Brief Tips**
 - Goal setting/planning; social participation, self monitoring, self control, staying positive, joining conversation/groups
- 3. Weekly coaching sessions via Skype with college students**
 - 10 sessions within 15 weeks
- 4. Coach training**
 - 1.5 hour virtual didactic & group discussion session
 - Review training manual & readings
 - Practice using app/creating goals/plans & reviewing tips & topics
- 5. Coach weekly supervision** (group phone call; in-person as needed)
 - Led by Clinical Psychologist & Occupational Therapist
 - Discuss logistics, challenges & successes; Problem solving; Support

Data collection / analyses

1. Type & number of goals achieved (*Content analyses of coach session notes*)
2. Pre- & post-test score changes on standardized measures completed by teens & parents (*Descriptive & non-parametric statistics & effect sizes computed*)
 - Total Behavioral / Social Problems & Social Competence Scales of Child Behavior Checklist (**CBCL**; parent-report) & Youth Self Report (**YSR**) (Achenbach, 1991)
3. Satisfaction & usability surveys completed by teens, parents & college student coaches (*Descriptive statistics, content analyses*) **Briefly summarized**

Teenager Characteristics

	TBI (n=9, 69%)	BT (n=4; 31%)	Total (n=13)
Age in years (Mean, SD)	16.59 (1.18)	18.25 (1.88)	17.15 (1.58) Range (14-19.5)
Sex, N (%)			
Male:	4 (44%)	1 (25%)	5 (38%)
Female:	5 (56%)	3 (75%)	8 (62%)
Race, N (%)			
Black:	2 (22%)	0 (0%)	2 (15%)
White:	7 (78%)	4 (100%)	11 (85%)
Loaner phone, N (%)	3 (33%)	3 (75.0%)	6 (46%)
Sessions completed (Mean, SD)	7.13 (3.52)	10 (0)	8.08 (3.15) Range (3-10)
Goals achieved (Mean, SD)	2.88 (2.10)	3.00 (2.31)	2.92 (2.07) Range (0-7)

Type and number of goals

(Goals achieved by teens: Mean=3; Range = 0-7)

Type of goal	Number of goals achieved
1. Spend more time with friends	16
2. Improve social communication	11
3. Try new activity with friends / boyfriend	4
4. Try new activity with family	3
5. Make new friends	2
6. Take lead role in a new activity	1
7. Help a friend / family member	1
8. Participate in a large social event	1
<i>Total number of goals achieved</i>	<i>39</i>

Pre-to Post changes

(Youth Self Report (YSR))

	TBI			Brain Tumor (BT)		
	Pre	Post	Cohen's d	Pre	Post	Cohen's d
Total Problems	53.88 (6.42)	50.38 (7.50)	0.54 ↓	45.33 (14.64)	51.33 (16.86)	0.49 ↑
Social Problems	54.75 (4.83)	54.50 (4.90)	0.07 ↓	52.67 (3.79)	59.67 (8.50)	0.93 ↑
Social Competence	44.00 (8.91)	48.75 (9.87)	0.52 ↑	44.00 (10.82)	40.33 (7.02)	0.78 ↓

*Wilcoxon signed rank tests **not significant** (total sample)*

Pre- to Post changes

(Child Behavior Checklist, CBCL, parent-report)

	TBI			Brain Tumor (BT)		
	Pre	Post	Cohen's d	Pre	Post	Cohen's d
Total Problems*	57.00 (7.82)	46.88 (8.22)	1.32 ↓	56.00 (2.65)	55.00 (5.20)	0.25 ↓
Social Problems*	57.00 (5.81)	52.63 (3.78)	0.87 ↓	65.00 (7.55)	62.67 (7.57)	0.61 ↓
Social Competence	40.14 (10.17)	44.43 (13.75)	0.35 ↑	45.33 (2.52)	45.67 (4.16)	0.05 ↑

* $p < 0.02$ (total sample)

Summary

- Results suggest SPAN offered **assistance with social participation goal achievement**
- Pre to post score differences reflect **positive changes for participants with TBI** and mixture of **positive changes (*parent measures*)** AND **negative changes (*teen measures*) for those with BT**
- **Satisfaction moderate to high overall** except for parents of teens with BT specific to **tips/topics** & for **teens getting in contact with coaches**
- **Coaching viewed very positively** by all participants

Limitations

- Small sample of convenience / no controls
 - Early phase of SPAN development
- Broadened enrollment for teens with BT midway due to enrollment challenges with teens with TBI
 - Content not specifically geared to Teens with BT
- App used in pilot designed for iPhone (~50 % had loaner phones)
- Problems installing app via Apple's Test Flight system
 - Some did not have access to app for initial coaching sessions (*developed/tracked goals & plans offline*)
- Coaches started at different time periods
 - Different amount of supervision & different skill levels

Future directions

- **Feedback from brain tumor survivors /parents**
 - Develop Topics /Tips to address their concerns
- **Improve usability of SPAN**
 - Make app easier to use /navigate; make usable on multi-platforms/ devices
 - Shorten / simplify key topics/brief tips
 - Clearer expectations for parents (*tailor to preferences*)
 - Examine usability post-SPAN
- **Explore use with other populations / settings & inclusion of other members of circle of support**
 - With additional stakeholder feedback & testing

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Thank You!

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