

Introduction

Social Participation: activities involving social interactions; associated with societal & community adulthood outcomes (i.e., independent living & employment) (1-5)

Adolescent young adult (AYA) brain tumor survivors face social challenges including social isolation & limitations in life roles, relationships, & social opportunities. (1, 3-5)

- Lack of evidence-based social participation interventions for this population.
- Current dominant intervention types (4):
 - peer mentoring/coaching
 - social skills training

Social Participation and Navigation (SPAN): 3-component intervention using virtual peer coaching, website with tips/ topics & goal planning web-based application to create/monitor goals, strategies, & plans to achieve social participation goals. (6-8)

- Originally designed for individuals with Traumatic Brain Injury (TBI) & later adapted for brain tumor survivors.
- Developed using iterative consumer driven design with 3 phases (i.e., stakeholder feedback; 4-week feasibility/ usability trial; 10-week pilot implementation trial) (6-8)

This research involved a [brief feasibility & usability trial](#) with 4 AYA brain tumor survivors.

- Project Purpose:** to examine goals & patterns of change in SPAN questionnaire items (social participation & related SPAN skills) following a 4-week usability SPAN trial

Methods

Phase 2 Procedures (Summer 2021):

Recruitment: Social Worker, East Coast, Children's Brain Tumor Foundation [CBTF]: email to hospitals of Greater Boston Area; CBTF social media outreach

Pre-coaching: Informed consent/assent & SPAN-specific pre-questionnaire

Session 1: Introductions, establish rapport, describe program & logistics

Session 2: Review goal-plan-do-review framework & begin goal development

Session 3: Support implementation of plan & review progress towards goals

Session 4: Prepare for closure & encourage continued use of skills/resources

Post-sessions: SPAN-specific post-questionnaire; Online Qualtrics usability feedback survey (AYA participants & parents of adolescents)

SPAN-specific questionnaire: administered pre & post SPAN intervention.

- 30 items addressing social participation confidence & involvement in activities at home, school, work & community.
- 15 items addressing SPAN skills (areas that SPAN intervention focuses on: goal planning, self-management & social communication). See radar plots for specific survey items.

Descriptive research design used: descriptive statistics including averages, standard deviations & effect sizes of SPAN survey item & group responses were computed

Data Analysis	
Radar plots: item-level individual & group (average) questionnaire scores	Compared item-level trends within & between participants Linked individual & average group changes
Item-level Cohen's d effect sizes computed to quantify degree of change among group	Related trends to open-ended responses & participants' goals Recorded goal outcomes

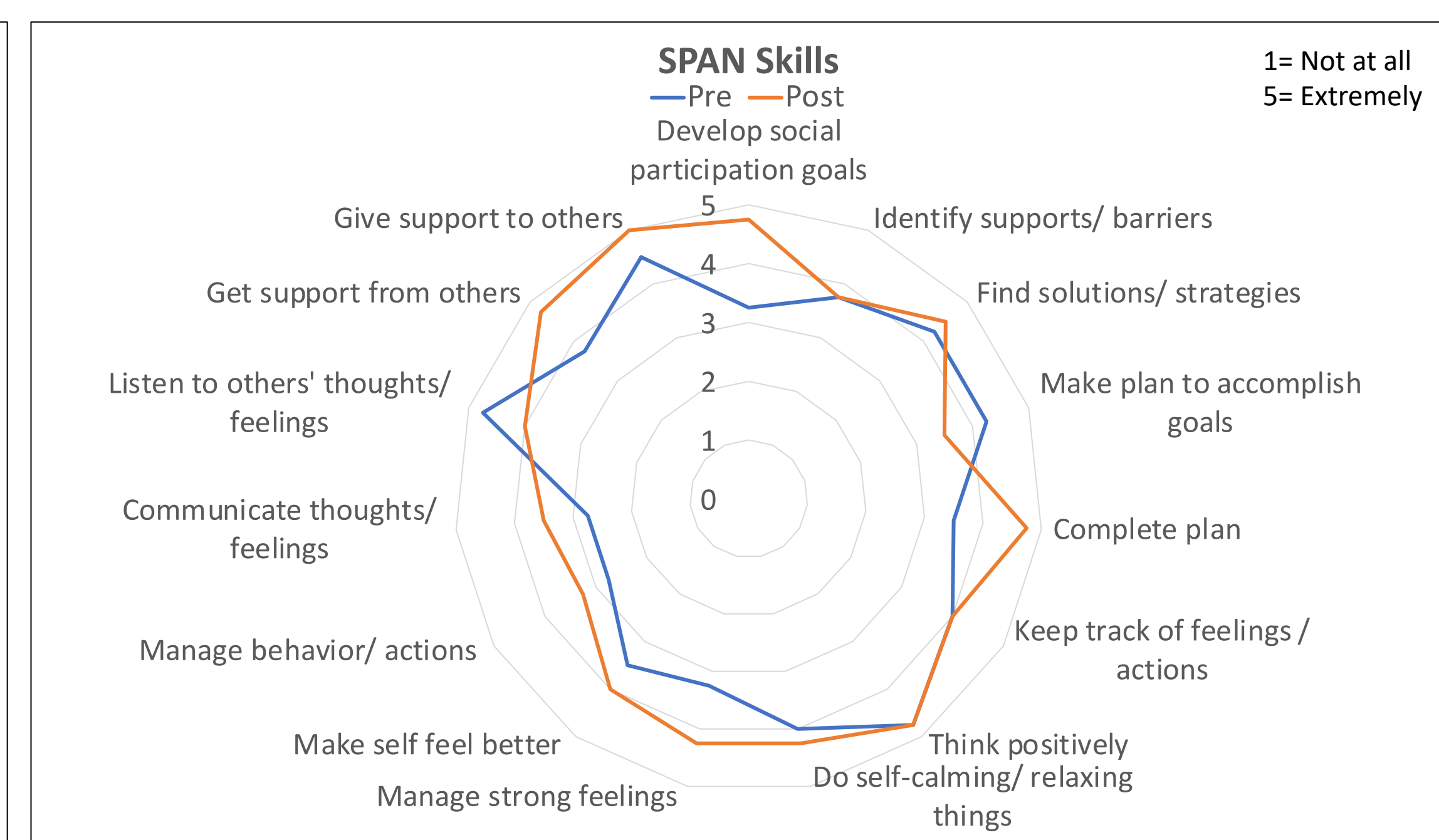
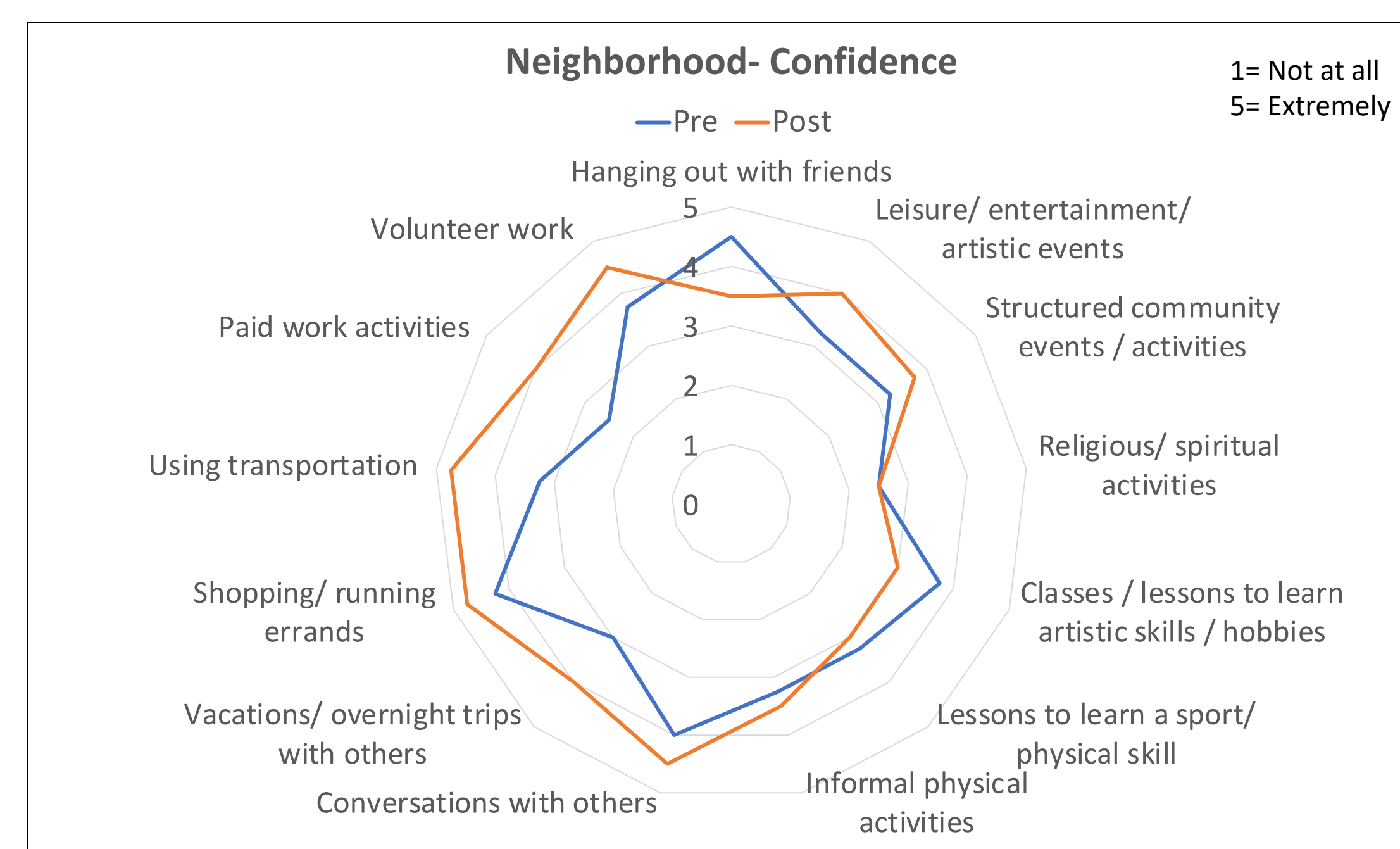
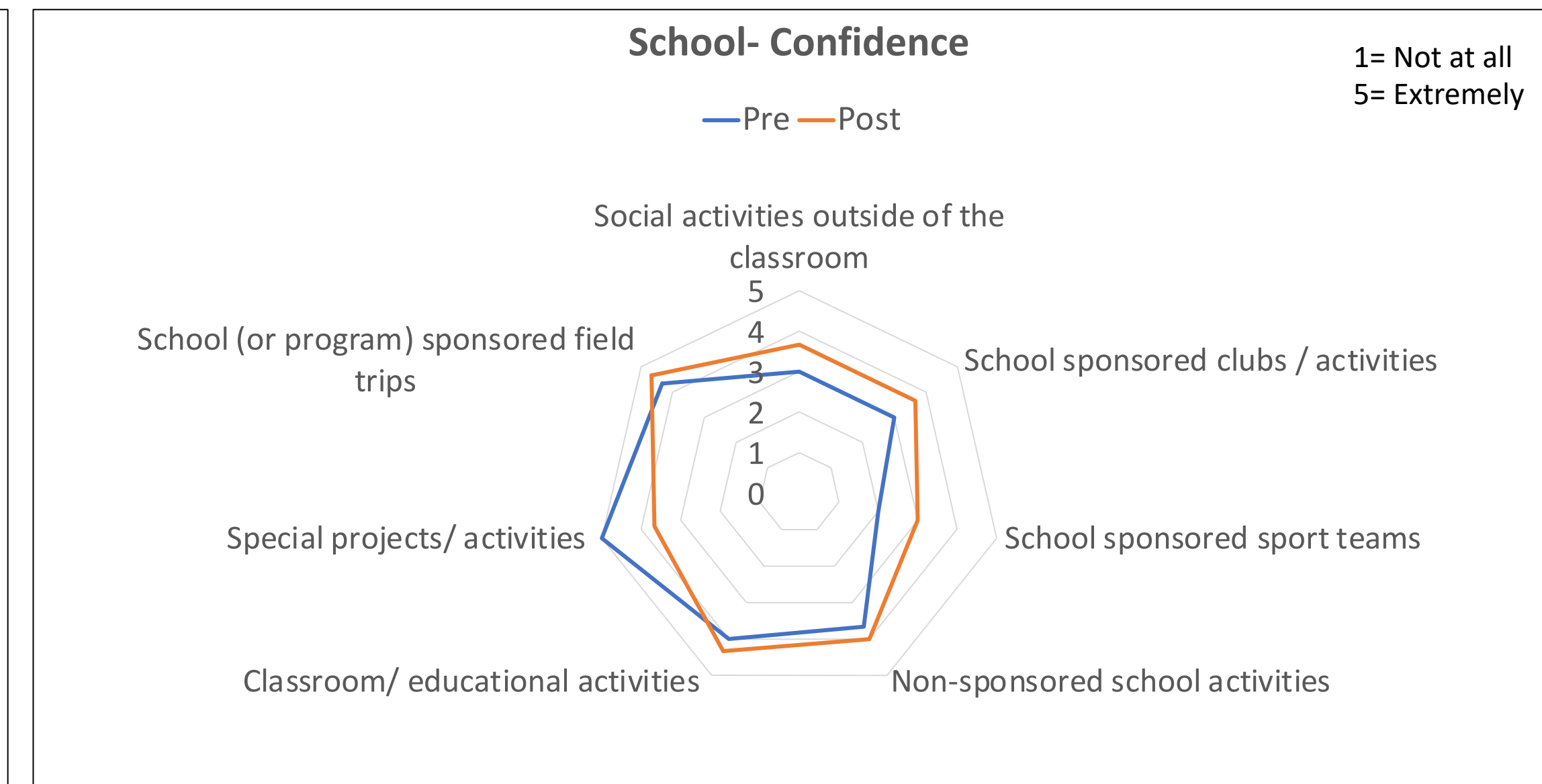
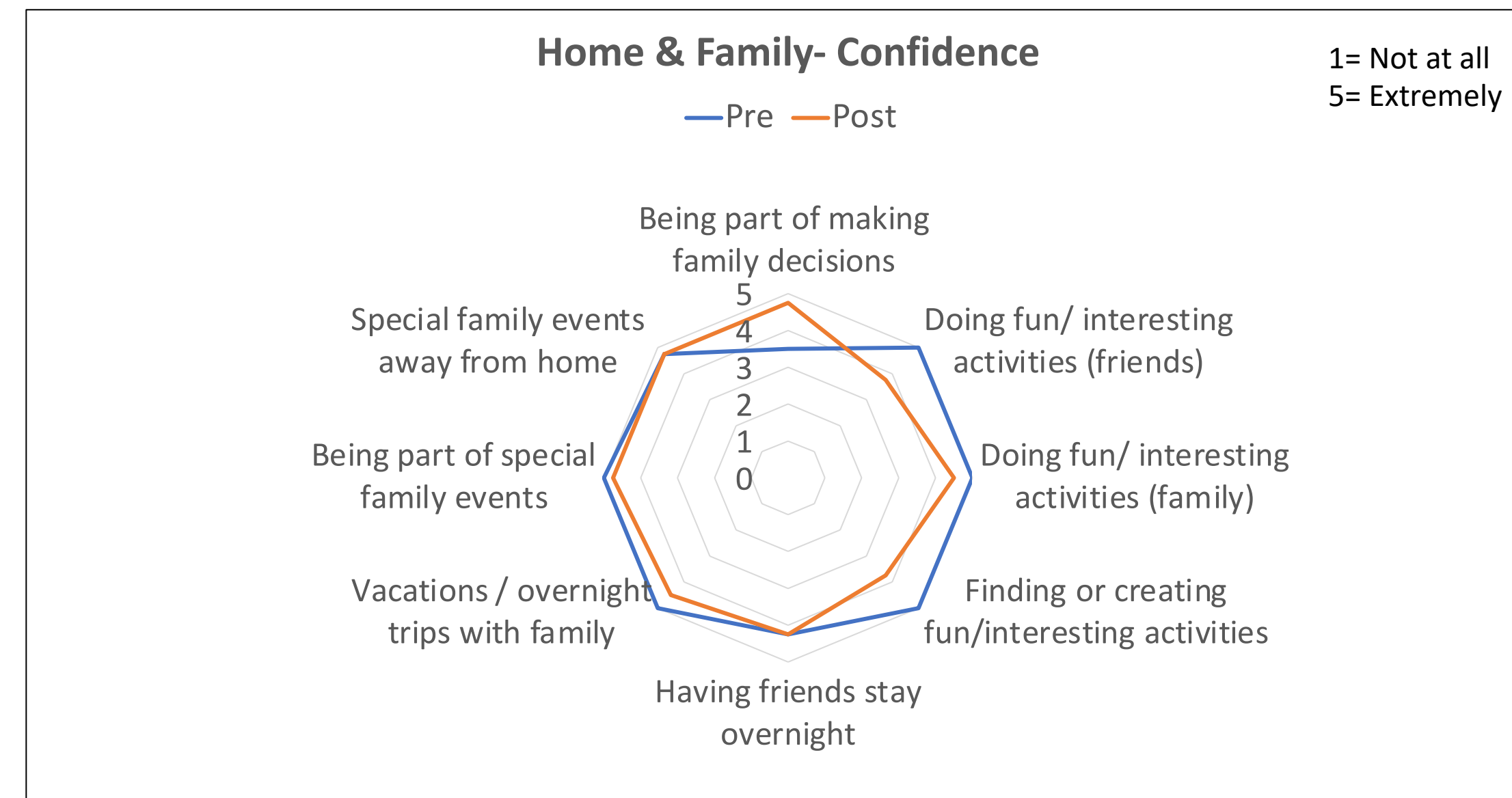
Results highlight confidence in radar plots, but trends related to involvement will be summarized.

Participants

Sample: 4 AYA brain tumor survivors (2 adolescents, 2 young adults)

- Age: 15-21 years
- Diagnosis age: <18 (between 3.5 months & 11 years); >6 months post-treatment during trial
- Sex: 2 females & 2 males
- Race and Ethnicity: 3 White, 1 Hispanic
- All exhibited social participation challenges (i.e., limited friends, impaired communication skills & social anxiety)

Results



Summary of Results

Goal	Progress	Barriers	Facilitators
Meet with peer in community	✓+	Impaired communication skills	Brain tumor community
Monthly zoom call with friends	✓+	Lack of transportation	Family
Be more outgoing/talk to someone new	✓	Impaired memory	Technological supports
Meet new student in class	~	Negative self perception	Self confidence
Get involved with work committees	+	COVID-19	Outgoing personality
Get involved with CBTF survivorship groups	+	Age	Therapist
Study for professional degree exam	✓	Limited friends	Involvement in activities/groups
Play games with family	✓	Physical disability	Optimism
Complete professional training program	+	Long-distance friendships	Connections with friends or others
Make new friend at school	~	Time/scheduling issues	Work
		Anxiety about new things	Familiar environments
			School advisor
			Fun/social activities

Key: Completed goal = ✓; Completed and continuing to work on = ✓+; Working on = +; Planned but not yet working on = ~

Results represent group averages, yet individual differences existed among participants

Home and Family

- High confidence & involvement ratings pre & post trial, however majority of items decreased in confidence ($d = -1.00$ to -1.98) & involvement ($d = -0.41$ to -1.73)
- Largest confidence increase in *being part of making family decisions* ($d = 1.65$)
- Largest confidence decreases in *doing fun/interesting activities with friends* & *finding/creating fun/interesting activities* ($d = -1.32$ & -1.98)

School

- Confidence increase in 6/7 items ($d = 0.16$ – 0.54); majority of items increased in involvement ($d = 0.17$ to 1.00).
- Confidence decrease in one item: *special projects/activities with others* ($d = -4.62$)

Neighborhood/Community

- Confidence increase in majority of items ($d = 0.20$ – 1.17); most items increased in involvement ($d = 0.14$ to 1.06)
- Decreased confidence in two items: *hanging out with friends* & *classes/lessons to learn artistic skills or hobbies* ($d = -0.80$ & -0.58)

SPAN Skills

- Increased confidence in 10/15 items ($d = 0.33$ – 2.00); largest increases in *developing goals & getting support from others*
- Decreased confidence in 2 items: *listening to others' thoughts/feelings* & *making a plan to accomplish goals* ($d = -1.14$ & -0.56)

Goals:

- Goals were a variation of family, school, community & work-related activities
- 3 participants identified 2 goals; 1 participant identified 4 goals
- 3 participants completed at least 1 goal; 1 participant did not complete a goal (but was working on)

Discussion/Future Work

- Bidirectional relationship between confidence & involvement:
 - Participants might feel more confident as involvement in social activities increases & they gain familiarity with social situations. (*Familiar environments identified as support*).
 - Participants might also feel more confident prior to engaging in social opportunities. As involvement increases, confidence can decrease.
- Confidence might increase despite limited opportunity for social participation (e.g., Covid-19, transportation challenges, or other barriers).
- Greater confidence & involvement in home/family setting might be influenced by supportive families. (*Family identified as support*).
- Average increase in confidence in school domain, despite only 1 participant enrolled in school at time. Many school activities incorporate transferrable skills (i.e., conversational; organizational) & creativity.
- Changes in confidence & involvement related to participants' identified goals. Goals might increase motivation & skill development.
- Covid-19 might explain decreased confidence/ involvement in home, community, or school & report of transportation as barrier.
- Average increase in SPAN skills confidence: likely due to participants actively working on goal setting & monitoring, communication, & getting support through peer coaching.

Study Benefits:

- Findings inform next larger SPAN trial
- Analyzing average group scores helped identify common item-level trends
- Determined item scores for each individual did not always align with group results. These scores highlight strengths & challenges of individual to best tailor interventions to fit their specific needs

Study limitations:

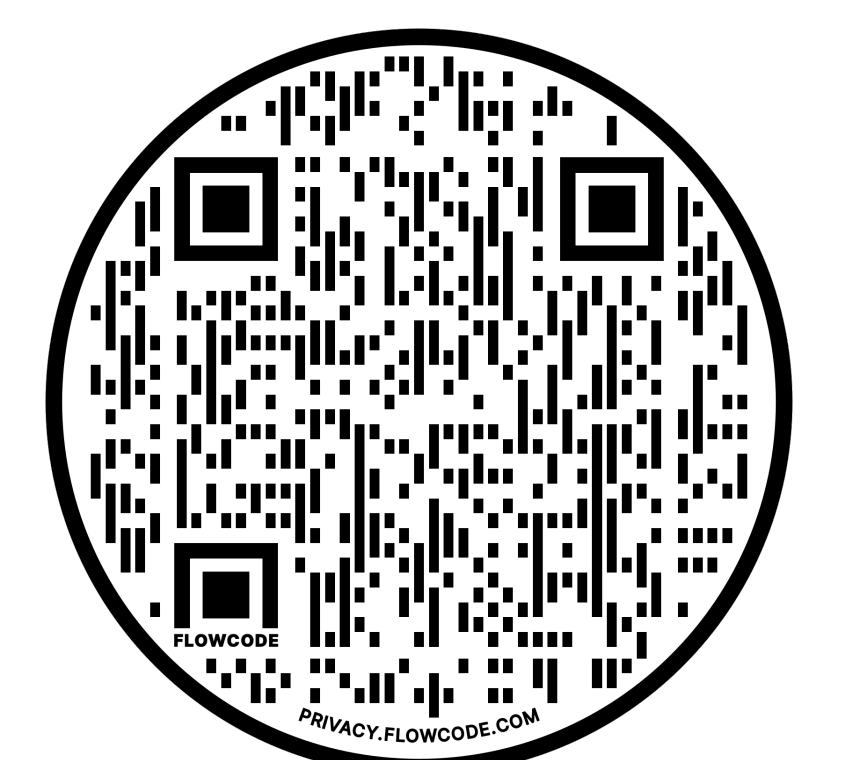
- Small sample size ($n=4$); results not generalizable
- SPAN Questionnaire is new measure with no study of psychometric properties
- Unable to determine causation between intervention & changes in social participation/SPAN skills

Thus, findings to be viewed with caution & can only suggest general trends for small sample of individuals

Future work:

- Larger 10-week pilot implementation trial of revised SPAN intervention for larger sample of AYA brain tumor survivors
- Study of psychometric properties of SPAN measures with larger sample size

References & Contact Info



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