In pursuit of a Behavior Intervention Technology to improve management of health-related self-care tasks for adolescents with spina bifida: Focus group data

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Spina Bifida (SB): The Basics

- **Physical issues**: bowel and bladder dysfunction, mobility concerns (wheelchairs, braces, etc.), pressure sores, shunt malfunctions
- **Neurocognitive problems**: attention deficits, impaired executive function
- Achieving appropriate **independence** from parents/caregivers is a major focus during adolescence

Why develop a BIT for youth with SB?

- **To improve adherence to health-related self-care tasks (e.g., catheterization, taking meds, etc.)**
  - Very few interventions available to improve adherence
  - mHealth interventions have been successfully used to increase adherence in other populations:
    - Diabetes
    - HIV
    - Asthma
- **Just like many other teens, youth with SB are active mobile phone users**
  - Anecdotal evidence
  - Preliminary 2012 data from teens with SB ages 13-18 (N = 29)
    - 79% send and receive text messages
      - 91% who use text messages have unlimited plans
      - 70% feel their lives would be worse if they could not text anymore
    - Keep in mind: 41% have smartphones

What role does cognitive ability play?

- Minimal research on mHealth interventions in individuals with cognitive disabilities
  - Borrow from mHealth research with TBI or elderly populations
- BITs may help be able to accommodate some cognitive deficits (e.g., executive function)
  - Relevant to other populations: depression, ADHD, TBI, etc.
- There may be special considerations to keep in mind
  - Easy-to-use interfaces
  - Train youth how to use interventions
  - Short instructions with appropriate reading level

Focus Group Data: Sample

- **Why**: The adolescents are the "experts"!
- **Who**: Youth with SB
  - 2 groups:
    - 10 youth 13 – 15 years old (M = 14.3 years)
      - 50% male
    - 12 youth 16 – 20 years old (M = 17.9 years)
      - 50% male
- **When**: Summer 2012
- **Where**: Summer camp for youth and young adults with SB in the Midwest

Focus Group: Procedures

- IRB approval
- Obtained informed consent and assent from parents and youth
- Occurred over 1 hour during camp weekday in the multi-purpose room
- Youth provided with snacks and drinks
- Focus group protocol – used in other BIT development research
  - Info. about use of internet, cell phones, text messaging, apps
  - SB-related issues that are hard to manage independently, benefits of becoming more independent
  - Proposed 2 types of interventions – get feedback

Focus Group Data: Procedures

- **Proposed 2 types of mHealth interventions targeting adherence to SB-related self-care tasks:**
  - Text message intervention: send text reminders to perform self-care tasks and provide feedback after user replies that task was completed
  - App intervention: a "one stop shop" for SB-related self-care tasks, including reminders, phone numbers, and facts
- **Incentives for using the intervention and completing SB-related self-care tasks**
  - i.e., earn points/rewards for responding that task has been completed

Focus Groups: What We Learned

- The majority of teens across both groups reported owning a mobile phone
- School: Although most adolescents reported having rules at school limiting their use of mobile phones, virtually all indicated that they have their phones with them most of the time
- In addition to health-related responsibilities (remembering meds, catheterizing on time, etc.), some adolescents discussed difficulties with more "everyday" responsibilities
  - Homework
  - Chores

Focus Groups: What We Learned

- **A majority in both groups preferred a text message-based intervention**
  - They are already familiar with text messages (easy to use) and already use text messages in everyday life
    - *"I prefer the texting one just because I check my messages more, and I really don't want to have another app." – 13-year-old female*
  - Teens would not need to have a smartphone to use the program
  - Concerns about smartphone app interventions
    - Not having a smartphone; Android vs. iPhone systems
    - Forgetting about the app after a few days and never using it again
    - Confusing, complicated, not user-friendly

Focus Groups: What We Learned

- **Intervention wish list**
  - Free/low cost
  - Personalized messages: not using a form message, having a variety of responses
  - Amount of time needed for the reminder varies per person and per task
  - Positive feedback: "Good job!" "Awesome!"
  - Visual way to track progress
  - Help with ordering medical supplies

Focus Groups: What We Learned

- **Developmental differences**
  - Self-care responsibilities:
    - Younger adolescents reported having more difficulties managing self-care responsibilities → greater need for intervention
  - Incentives:
    - 13-15 group: indicated interest in incentives (iTunes downloads, points, computer game levels, etc.)
      - *"I'd be motivated to do it (self-care task) because of the reward." – 14-year-old male*
    - 16-20 group: intrinsically motivated; felt that external incentives should not be used for health responsibilities
      - *"I don't think it's necessary to get a prize for something you're already expected to do." – 16-year-old female*
  - Use of technology:
    - Older adolescents reported that they use their phones more often, with most texting every day
    - More adolescents in the 16-20 group reported already using apps/alarms/website-to-text programs on their phones to help manage health-related responsibilities

Implications

- There is a need for a BIT to aid adolescents with SB in their management of health-related *and* non-health-related responsibilities
  - Greatest need for younger adolescents (?)
- Although a text-message-based intervention was preferred by most adolescents, issues related to smartphone apps may be adequately addressed through training and coaching by clinicians
- Individualization is key – different goals, incentives
  - Goals and incentives need to grow with the adolescent