Technology Use in Individuals with Fragile X Syndrome: A Study to Inform the Design of a Decision-Support Application

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Introduction

- Traditionally, individuals with intellectual and developmental disabilities have primarily used technological devices for communication and mobility. However, these devices are now also used to enhance cognition, improve social skills, and support activities of daily living.

- Use of tablet-based devices by individuals with intellectual and developmental disabilities has grown rapidly in recent years. Apple alone features more than 500 applications in the special education section of its App Store.

- Yet, not much is known about technology use, ability, and engagement level of individuals with fragile X syndrome (FXS).

Aims

- To explore how individuals with FXS are using technology and how it can be devised to meet their needs.

- To inform the development of a tablet-based decision aid to help those with FXS make decisions about clinical trials.

Methods

Design

- A mixed method design was used that consisted of the following: 1) An online quantitative survey of parents of individuals with FXS, 2) A set of in-person qualitative interviews with individuals with FXS and their parents.

Participants – Online Survey

- The quantitative survey was launched through Our Fragile X World, a survey research registry.
  - Families of individuals with the full mutation and aged of 14 to 40 years were invited to participate
  - A total of 198 families responded to the survey
  - Families completed the survey about a preselected child in their family:
    - 81% were males
    - The mean age was 24.4 years (± 9.7 standard deviation), 28% were under 18 years of age

Participants – Qualitative Interviews

- The in-person qualitative interviews were conducted with six individuals with FXS:
 - Five males and one female; the mean age was 22.3 years

Measures

- During winter 2014, 53 online survey items were administered, asking about technology use, including what types of technology individuals with FXS use, how they use it, and their level of engagement.

- In fall 2013, qualitative interviews were conducted, each lasting approximately 60 minutes, to assess the following: 1) Technological abilities, 2) Level of engagement with specific features of six applications (e.g., narratives, video, voice response).

- The level of engagement was rated on a five-point Likert-type scale, where
  - 1 = Refused to interact
  - 2 = Limited engagement
  - 3 = Moderate engagement
  - 4 = Active engagement
  - 5 = Hyper engagement

Results

Online Survey

- The vast majority of households owned at least one electronic device, with 78% of families indicating they own a tablet computer (see **Figure 1**)

Figure 1. Electronic Devices Currently in the Household
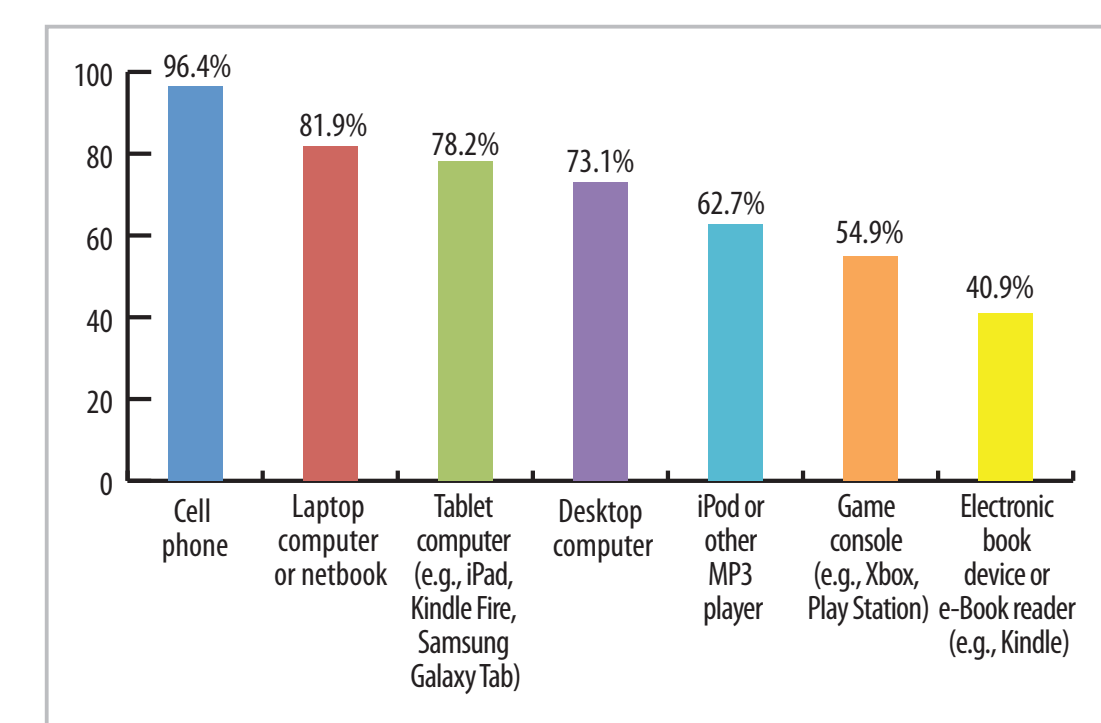
- 50% of families reported they have software applications or "Apps" on their cell phones that help them track or manage their health, and 69% said they use their cell phones to research health or medical information

Figure 2. Time Child Spends Per Week Using Electronic Devices for Work, School, or Play
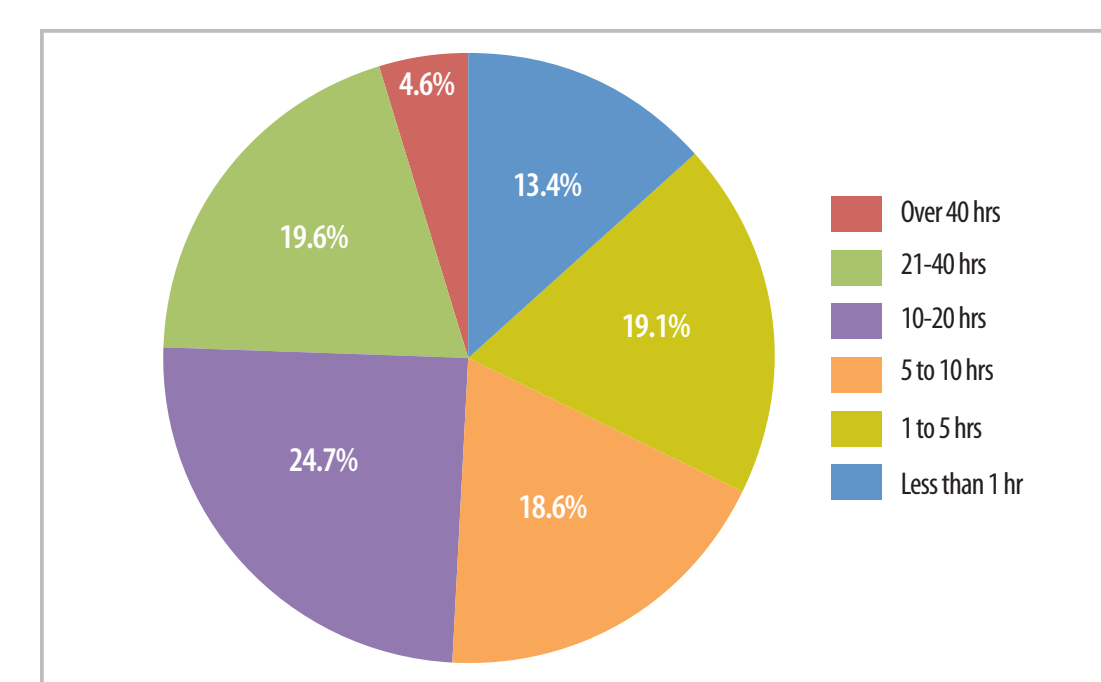

- Approximately half (51%) of families reported that their child uses an electronic device for work, school, or they play with it at least 10 hours each week (see **Figure 2**)

Figure 3. Internet Activities in Which the Child Engages
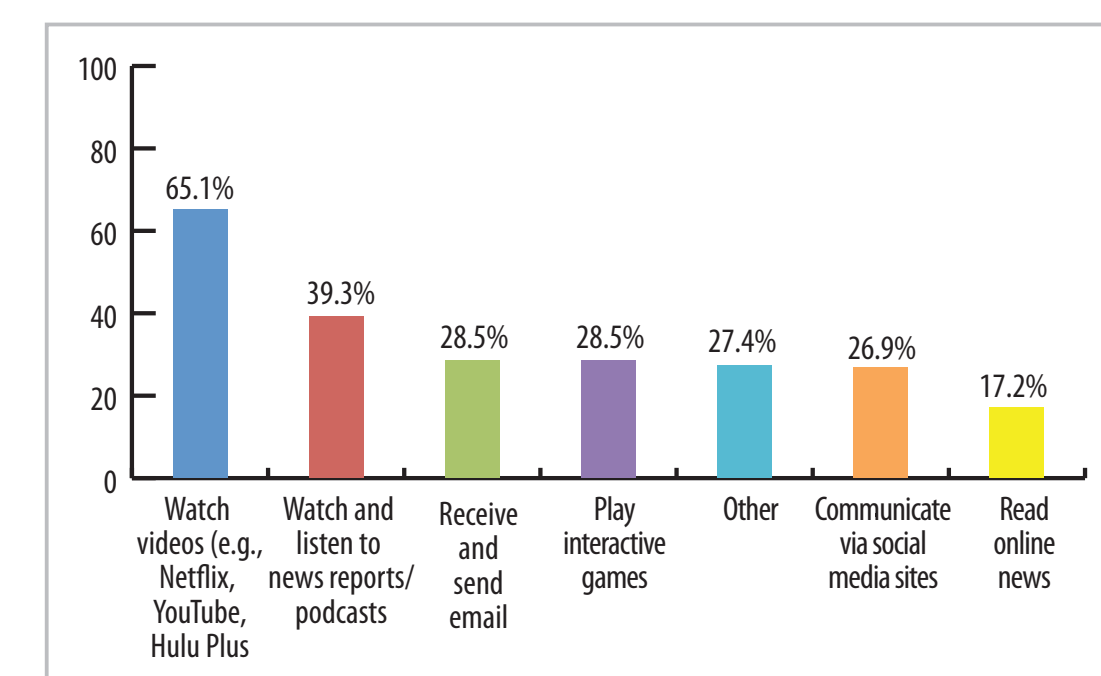
- When accessing the Internet, parents reported that their child mostly watched videos (e.g., Netflix, YouTube, Hulu) or listened to or read news reports or podcasts (see **Figure 3**)

Figure 4. Web Sites or Apps Typically Used by the Child
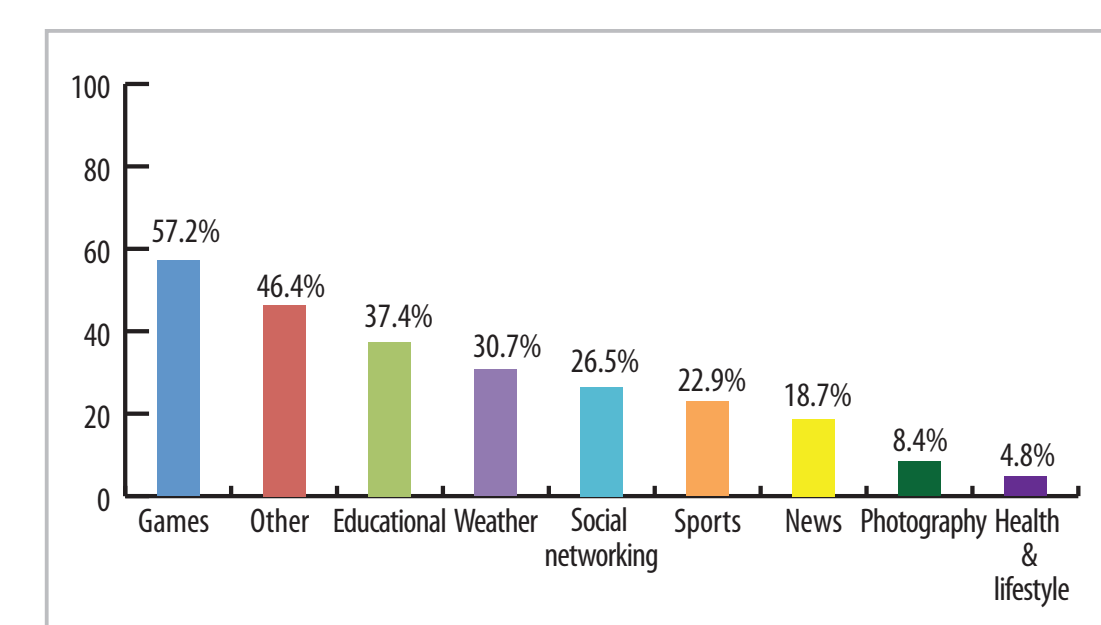
- When using a desktop computer, parents indicated that their child was most likely to use it to play games (57%), visit educational Web sites (37%), or get the weather report (31%) (see **Figure 4**)

Figure 5. Child's Level of Engagement with Electronic Devices
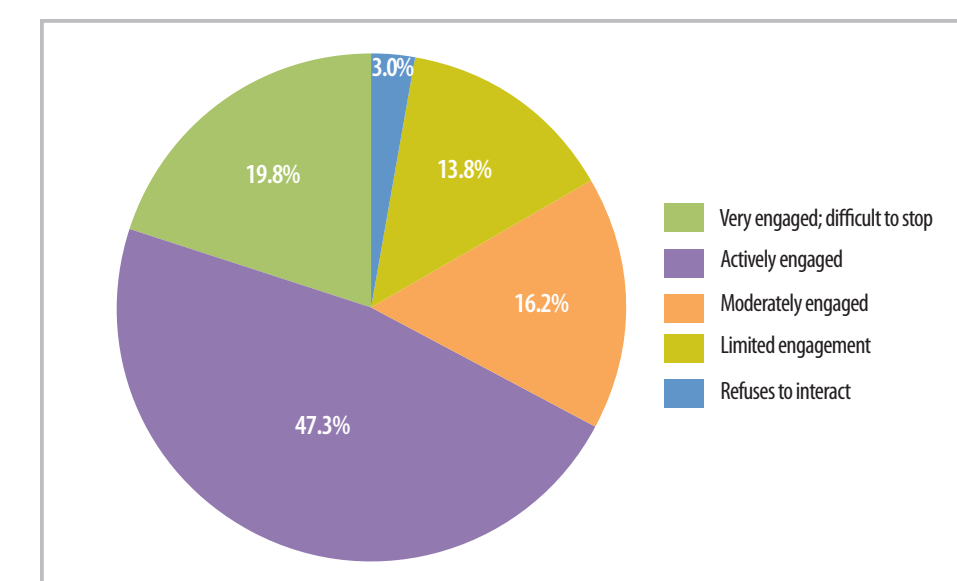
- Typically, parents say their child is actively engaged when playing with electronic devices (see **Figure 5**)

Qualitative Interviews

- Participants had a fair amount of experience with various types of technology (e.g., computers, smart phones, e-readers) and were very comfortable using a touch-screen tablet (see **Table 1**).

Table 1. Participants' Technology Experience

Participant	iPad	iPhone	iPod/Touch	Tablet (e.g., Kindle Fire, Nook)	Computer (i.e., desktop, laptop)	Smart Phone	Other
1	•		•		•		
2				•	•	•	•
3	•		•		•		•
4		•			•		•
5					•		•
6	•	•			•	•	
Total with experience	n=3	n=2	n=2	n=1	n=6	n=2	n=4

- Parent and interviewer ratings regarding engagement level were fairly similar; both agreed that participants were moderately to actively engaged with the iPad during the interview (see **Table 2**)

Table 2. Engagement Ratings by Interviewers and Parents

Participant	Interviewer Rating (Average Across all 6 Apps)	Parent Rating
1	3.7	3
2	3.3	3
3	2.7	4
4	3.7	4
5	3.0	5
6	2.2	4
Average	3.1	3.8

- Most participants demonstrated greater interest in tablet-based applications that were interactive (e.g., allowed them to control features, move icons on the screen) and those that provided some type of feedback or reinforcement.

Discussion

- Individuals with FXS and their families are actively using technology in their daily lives.

- Given the level of engagement and comfort using technology, a tablet-based application may be a promising strategy for informing individuals with FXS and their families about health-related options such as clinical trials.

- Specific technological features may be useful to include when designing tools to promote informed decision making (see **Table 3**).

Table 3. Technical and Conceptual Design Recommendations

Technical and Conceptual Design Recommendations	Execution/Delivery Examples
1) Provide options for the participant to control and interact with content	• Customizable setting selections, appearance, and activity choices • Sorting activity to demonstrate understanding of risks and benefits • Audible questions directed at participants so they can answer based on their preference (no right or wrong answers) • Allow for dragging and dropping answers (words/pictures) into sentences and/or questions with a blank
2) Demonstrate cause and effect	• Design context (e.g., animated words when tapped) • Clinical context (e.g., understanding the implications of their choices)
3) Combine a story and game approach to convey information	• Incorporate "levels or chapters" or other incentives to indicate progress • "Roadmap" or a checklist indicating progress through decision tool • Possible graphic novel approach
4) Heighten engagement with strategic design elements	• Clearly marked and consistent navigation cues for page turning (e.g., labeled arrow buttons) • Obvious hotspots that draw attention to themselves (e.g., floating or pulsating objects) • Forced pauses or pacing to prevent skimming through pages • Animated images that are vibrant (i.e., colorful) and age appropriate
5) Incorporate personally relevant components	• Insert a participant's name into text throughout • Insert a photograph of a participant

More Information