INCREASING SELF-ADVOCACY OF ADOLESCENTS WHO STUTTER THROUGH INTERACTIVE NARRATIVE DESIGN

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Introduction

Many persuasive games allow players to role-play to better understand an individual's or group's point of view. No known studies have evaluated the ability of patients (non-game designers) to tell the story of their own disease/disorder through game design.

Speech and language disorders, such as stuttering, often negatively impact an individual's quality of life (Wolter, DiLollo, & Apel, 2006). One approach to help patients with this issue is narrative therapy, an approach that can benefit multiple patient populations including those who stutter (DiLollo, Neimeyer, & Manning, 2002; Wolter, DiLollo, & Apel, 2006). Narrative therapy encourages a patient to shift the focus of their life story (or personal narrative) from a disorder-centric narrative (where the disorder is in control) to a patient-empowered narrative (where the patient has control over the disorder). While the goal of narrative therapy is to change the patient's personal narrative over the course of therapy, both narratives (disorder-centric and patient-empowered) are a valid representation of the patient's experience. Therefore, the ability to intertwine the two forms of the narrative one gives the creator (the patient) the ability to design an interactive experience for others (e.g., family, friends). Rather than simply telling others about how the disorder impacts his/her life or asking others to read a static narrative about the impact, both of which are in the third person, the interactive narrative acts as a simulation, allowing others to experience consequences of choices the patient has to make from the patient's point of view (first person).

The act of creating a patient-generated interactive narrative (PGIN) may provide a unique way to increase a patient's self-advocacy. Prior literature indicates that writing one's own life story can be a method of self-advocacy (Meininger, 2006), but creating an interactive experience may further increase patient self-advocacy. We explore this idea through a study of individuals attending a summer camp for adolescents who stutter (AWS). The AWSs, with the help of graduate student clinicians (GSC), created and mixed earlier and later versions of the personal narrative using Twine (twinery.org), an open-source software for designing narratives. We discuss the results of a group interview with summer camp attendees post-PGIN creation.

Methods Participants

Fourteen AWS [10M, 4F; Age: M=14.5 years (12-18 years)] attended the weeklong summer camp (UISPEAKS). Each AWS was paired with a GSC [2M, 12F; Age: M=23 years (22-30 years)].

Study Procedures

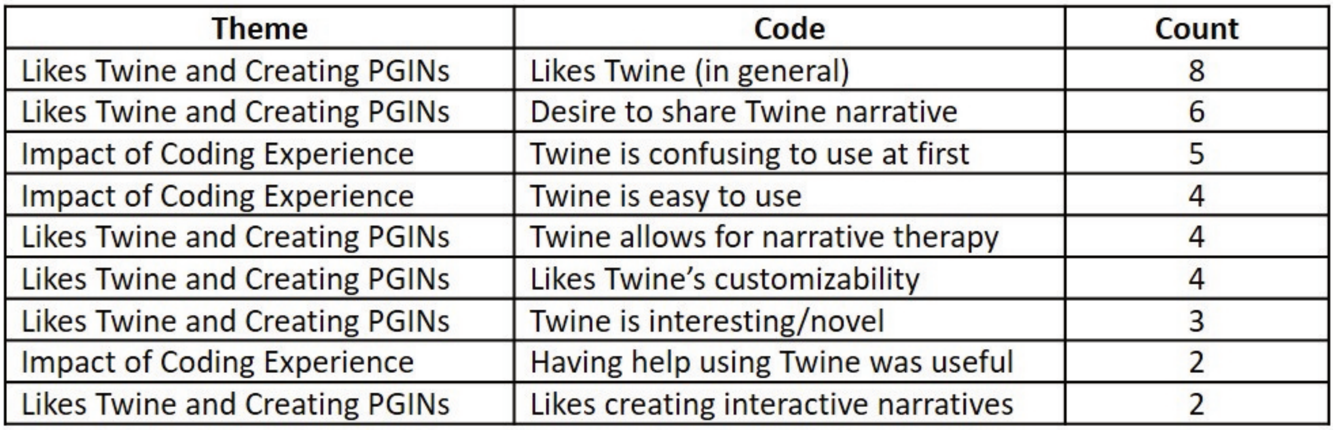
Prior to UISPEAKS, the GSCs received training in using Twine through a one-hour workshop led by author C.K. On the second day of the camp, each AWS and his/her GSC created the initial version personal narrative and copied it into Twine in a 1-hour session. On the fifth day, each AWS and GSC pair participated in a 1-hour session to “thicken” the interactive narrative using Twine with the GSC prompting the AWS to add patient-empowered alternatives based on experiences during camp.

Outcome Measures

At the end of UISPEAKS, a semi-structured group interview was conducted with all AWSs, and a follow up survey was emailed to GSCs. Results from the interview and surveys were analyzed using consensus coding (Braun & Clarke, 2006) between two coders (authors L.K. & C.K.). After creating the codes, codes were grouped into emerging themes through affinity diagramming (Beyer & Holtzblatt, 1998).

Results

In this extended abstract, we focus on the main findings from the group interview with the AWSs. The results are summarized in Table 1, and emerging themes are further explained below.



Theme	Code	Count
Likes Twine and Creating PGINs	Likes Twine (in general)	8
Likes Twine and Creating PGINs	Desire to share Twine narrative	6
Impact of Coding Experience	Twine is confusing to use at first	5
Impact of Coding Experience	Twine is easy to use	4
Likes Twine and Creating PGINs	Twine allows for narrative therapy	4
Likes Twine and Creating PGINs	Likes Twine’s customizability	4
Likes Twine and Creating PGINs	Twine is interesting/novel	3
Impact of Coding Experience	Having help using Twine was useful	2
Likes Twine and Creating PGINs	Likes creating interactive narratives	2

Table 1: Common codes from the group interview with AWSs about using Twine for creating PGINs.

Theme 1: Impact of Coding Experience

Twelve of the fourteen AWSs did indicate prior coding experience. This was partially reflected in the theme “Twine is easy to use” (four codes) although there were five codes indicating that “Twine is confusing to use at first.” These findings suggest that prior coding experience may provide some limited benefit in using Twine for narrative therapy but support using the program may still be needed (“Having help using Twine was useful”, 2 codes).

Theme 2: Likes Twine and Creating PGINs

The results indicate that, overall, the AWSs had positive views of creating their own interactive narratives in Twine. None of the AWSs had used Twine previously, but many AWSs commented that they liked Twine in general (8 codes), liked the program's customizability (4 codes), and that Twine is a good program for creating interactive narratives in narrative therapy (4 codes). The AWSs reported they liked creating interactive narratives (2 codes) and liked the novelty of the experience (3 codes). In addition, multiple AWSs expressed a desire to share the Twine narrative with others (e.g., friends, family; 6 codes). One AWS stated that she planned to share her interactive narrative in Twine for "self-advocacy." These results support the use of Twine for creating PGINs because it is a positive experience for AWSs.

Discussion

While another recent study examined the impact on game designers of creating a game based on their own illness/disability (Danilovic, 2018), this is the first known study to evaluate the ability of patients (non-game designers) to tell the story of their own disease/disorder (stuttering) through game design. The results provide preliminary evidence that using PGINs can be a positive experience for AWSs, and that AWSs want to share PGINs with others. Future studies should further explore the impact of PGINs in other patient populations. In addition, future studies should follow up with patients to determine whether patients do share PGINs with others and the impact that has on the patients.

References

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