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A Transmedia Narrative Framework for Pediatric Hearing Counseling

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Abstract. To help fill the gap in pediatric communication tools and support child-centered care in pediatric hearing care, we designed and evaluated a novel narrative transmedia tool for facilitating communication with children during pediatric audiology and speech- and language therapy appointments. The digital tool integrates methods from narrative and play therapy, and applies a novel transmedia narrative framework using 360-degree video and smartphone-based Virtual Reality (VR). The tool was evaluated in three case studies. The findings suggest that the tool was effective in engaging the children in conversation about their hearing, supporting the specialists in exploring the functional impacts of the children's hearing loss. Through co-participatory design, implementation and evaluation with hearing care specialists, it became clear that such a multi-platform transmedia tool, combining interactive digital narrative and emerging narratives, represents a promising avenue for facilitating child-centered communication during pediatric hearing care appointments.

Keywords: Patient-centered care · Transmedia narrative · VR · Emerging narrative · Pediatric hearing care · Narrative therapy · Play therapy · Communication.

1 Introduction

In adult and pediatric health care, communication and person-centredness serve as the basic elements for health literacy, but also as the main indicators of the quality of care received by children and their families [38],[3]. However, rather than focusing on promoting more effective child and care provider communication, and addressing the child's individual needs for treatment, new pediatric digital tools have been much more concerned with diagnostic or physical rehabilitative uses. To help fill this gap in current applications and to support child-centered care in pediatric health care, we designed and tested a novel narrative transmedia tool for enhancing child and care provider communication for pediatric audiology and speech- and language therapy appointments. Pediatric hearing care can be considered a collaborative process through which

the child, the parent(s), the therapist, the child’s teacher(s), and the audiologist, all must work together to support the child in the treatment process. It is therefore crucial that in this process the child’s voice and needs are being heard and addressed, as the inability to meet them can have serious effects on the child’s well-being, their speech- and language, and their psycho-social development. The digital application, designed together with hearing care professionals, integrates methods from narrative and play therapy, and uses a tablet computer, a smartphone, and a smartphone-based VR headset to help facilitate more effective child and care provider communication. By applying a novel transmedia narrative framework, the tool aims to support the goals and objectives of the appointment, while promoting the child’s self-advocacy and self-efficacy skills through the child’s active participation and engagement during the appointment.

2 From Narrative and Play Therapy to Digital Tools

When designing new technological solutions and tools in healthcare, designers and developers frequently rely on the translation of existing clinical and therapeutic methods, “[I]t is vital to understand the conventional practices and processes in the therapies when developing technology-based interventions and translating this in-depth understanding in the technology design.” [30], [18]. This is particularly pertinent when designing novel tools for pediatric populations. Stemming from person- and family-centered practices, the concept of Child-Centered Care (CCC) relies on effective communication between the child and the care provider, recognizing the child as a responsible and active participant in their own care [10]. In pediatric therapy and counseling, a child-centric approach is often realized using methods and techniques from narrative and play therapy [4], [29], [15]. Through the language of play, play therapy allows the therapist to utilize the process of projection through which internal events are attributed to (play) objects and characters [17]. On the other hand, narrative therapy refers to an approach where the patient’s stories are used in the treatment process to “re-author one’s own story”, in which the externalizing process supports the patient in deconstructing problem-saturated stories, allowing them to be shaped into new narratives through unique outcomes [23], [13], [8].

The critical relationship between hearing loss and speech- and language development is well recognized, which can perhaps also explain why in the past, narrative approaches in pediatric hearing counselling have been considered to be problematic due to their logocentric nature [11]. However, as it has been demonstrated more recently, through combining narrative approaches with play therapy, they can allow for the necessary flexibility and sensibility for adapting to the child’s developmental level and in effect, help enhance the communication process [2]. Moreover, [9] draw attention to the importance of the body when involving children in story authoring tasks. While recognized as central to the experience of play, [9] suggest that “enactment, through imagination, leads the child to better, richer and more coherent storytelling.”

When introducing technology-based solutions that rely on existing therapeutic interventions, it is also vital to consider the children’s changing communication and play habits in the current digital age [14].

2.1 Interactive Digital Narrative in Therapy

One of the new modes of digital communication and representation, incipiently being used in narrative therapy and counseling, is interactive digital narrative (IDN). As proposed by [27], IDN poses a number of advantages for health interventions, including, but not limited to, introducing a more flexible and engaging way for patients to engage with care providers, increased accessibility to materials, as well as possibilities for customisation and personalization that respond to the needs and preferences of the user [27].

As a therapeutic intervention tool, IDN has been investigated in different pediatric populations, including pediatric cancer patients [36] and in pediatric hearing counseling [2]. With respect to the use of IDN based tools in pediatric hearing care, [2] suggest that “given a specifically designed emergent narrative system, structured around specific counseling goals and supported by a context-specific adaptation of scaffolding conversations maps, digital interactive narrative tools can be potentially useful in engaging and facilitating communication with children during counseling and/or therapy sessions.” While IDN in pediatric counseling can in many ways still be considered in its infancy, recent findings and growing interest suggests its potential for applying a more child-centric approach whilst helping to promote more active participation in the care process [36], [2], [37].

More recently, IDN has also been explored through the integration of immersive technologies. It has been proposed that VR as a narrative medium can support changing concepts of the self: “through novel utilization of the storytelling medium, a person finds themselves immersed and starts changing their self-concepts more quickly and easily than in reality.” [12]. Research that has examined VR in pediatric psychology and speech- and language pathology, suggests that controlled VR environments can allow children to engage with background narratives more effectively [24], and provide means for training and building communication skills that can be generalized to real-world experiences [6]. Although little is still known about the potential of VR for diverse applications of IDN in health care, we suggest that it may potentially enhance narrative based counseling and therapy processes.

3 Design

The tool was designed for initial and follow-up pediatric hearing counseling appointments and integrates methods from narrative and play therapy, as well as elements from some of the few existing pediatric hearing counseling tools [22], [19] developed by the Ida Institute. The tool aims to introduce a narrative communication platform for facilitating more effective communication during the

appointment. In this case, we define a narrative communication platform as a foundation for reciprocal conversation and emerging narratives, built around specific themes embedded in pre-constructed fictional or non-fictional narrative elements. While by emergent narrative we refer to a narrative that is not pre-scripted, or pre-defined but which emerges through the interaction in the given context, “in the style of improvisational drama, rather than the authored narratives in more widespread use” [1], [20]. The core design of the narrative framework applies a transmedia approach [16], distributing three different stages of the counseling process across two different media, involving an application on a tablet-computer and 360-degree video scenarios in mobile-VR.

The tool was designed together with hearing care professionals with whom we outlined essential requirements, and the key considerations for the tool through a co-design approach. To ensure a family- and child-centered focus, we worked in close collaboration with specialists from the Ida Institute, a non-profit organization working with integrating person-centered care (PCC) in hearing care. We also reviewed relevant studies, materials, tools and articles that had previously addressed considerations for pediatric counseling applications outside of just diagnostic purposes [7] [25], [2], [33], [26], [22], [19]. Additionally, we conducted 10 structured and semi-structured qualitative interviews with hearing care professionals, including a senior audiologist, a small-children’s speech and language consultant, a school children’s speech and language consultant, and an experienced speech and language pathologist.

Based on our research, we identified key considerations for the tool as follows: (1) ease of use and clear instructions, (2) fun and engaging for the child, (3) focus on the functional impacts of hearing loss in everyday scenarios, (4) allow documenting concise and key takeaways, (5) allow for providing a handout or take-at-home resource for the patient, (6) take into account the time constraints of the appointment, (7) support facilitating troubleshooting skills and communication strategies. These elements served as the underlying pillars for the general frameworks and design.

Moreover, as the tool has a narrative focus, it was important to consider the adaptability of the tool for children of different ages and developmental levels. It has been suggested that children from around age 6 are only beginning to improve their narrative skills, with preteens typically expressing relatively high-level narrative skills [5]. However, as this clearly differs from child to child, the age-group for the tool was broadly defined for children aged between 5-13. Additionally, we conducted a number of usability tests throughout the design and development process. This included among others, early usability testing with participants recruited through convenience sampling, followed by usability testing with normal hearing children (NH) in the intended age group.

3.1 Design and implementation of the Narrative System

A transmedia approach was adopted to enrich the narrative elements for supporting emergent narratives, to subsequently help establish the narrative communication platform, but also to promote active user participation and involve-

ment throughout the session. As mentioned, the narrative framework distributes three different stages of the counseling process across two different media (see 3.2 Counseling Stages below). Making use of the specific affordances of the two different media, i.e immersion in the case of VR, and children’s gameplay possibilities on tablet computer [21], each stage in the two media introduces new types of content and narrative elements to support context-specific open-ended emergent narratives. Moreover, the tasks and questions in the tool take inspiration from, and integrate elements from existing pediatric hearing counseling tools [22], [19].

Firstly, on the tablet computer, the user is introduced to initial narrative elements, the context and the character (See Fig.1.), and is thereafter asked to prioritize and evaluate different communication environments (school/kindergarten, home, playground) (See Fig.2).

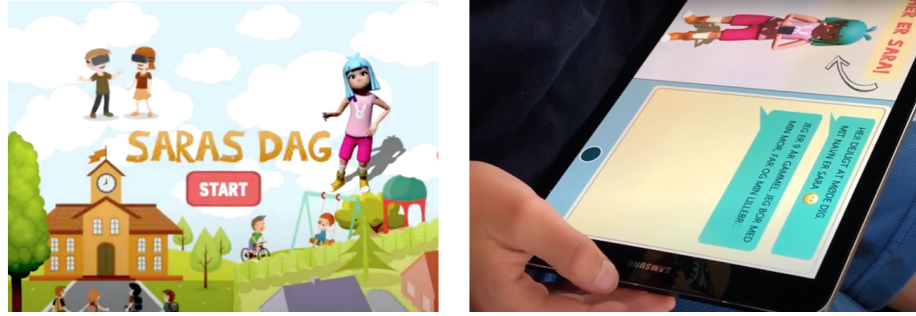


Fig. 1. Introduction on the tablet computer. On the left, screen capture of the start screen. On the right, character introduction.

The three environments were chosen based on their pertinence and relevance, as advised by our participating specialists. After the introductory part, the user is asked to select one specific communication environment (the setting) they would like to explore further. The guiding thread is to help the character (Sara), who suffers from hearing loss to identify potential issues and challenges in the chosen communication environment, to subsequently encourage exploring and defining specific communication strategies for that environment. In this initial stage, through the interactive tasks and questions, the system also obtains relevant information about the user to personalize the experience, support the selecting of the most relevant communication environment, and to provide post-session documentation for the specialist.

Subsequently, a 360-degree video scenario introduces the setting and the point of view. The user can then experience their previously selected environment through ‘Sara’s eyes’, using a mobile-VR head-mounted display (HMD)(See Fig.3.). All three possible scenarios are produced as scripted 2-3 minutes long one-shot 360-degree videos. To elicit context-specific emergent narratives, each



Fig. 2. Screen capture of interactive tasks and questions in the app on the tablet computer. On the left, prioritization of the three different communication environments. On the right, evaluation of the prioritized communication environments. (Given the original context of the implementation and evaluation, the texts are in Danish language)

360-degree video concurrently conveys a number of typical situations that a child with hearing loss (HL) might encounter on a day-to-day basis, corresponding to the specific communication environment. When designing these three scenarios, it was important to take into consideration the desired margin for user-interpretation, as well as the opportunities for achieving this using the 360-degree video narrative medium. It was hypothesized that allowing more freedom in the interpretation of the scenarios, instead of introducing explicit narratives, could better support the therapeutic goals of the system. Although the user was expected to freely explore the scenario, it was nevertheless important to support keeping the focus on the specific context of the chosen communication scenario. This was done through directing the user’s attention in the scenario through concurrent scripted situations. These scenario-specific situations were established based on an analysis of relevant materials, information gathered from the conducted semi-structured interviews, and observational data from Ida Institute’s ethnographic videos. To encourage the user in adopting the character’s perspective during the experience, all 360-degree video scenarios include a first-person avatar perspective of the character’s virtual body.

Returning to the tablet app, the user is encouraged to reflect on their VR-experience and use the introduced narrative elements in a play activity on the tablet computer (See Fig.4.). The play activity aims to elicit and support the sharing of emergent narratives to meet the embedded counseling goals. The design for the play activity presents the user with a modifiable ‘canvas’, where pre-arranged elements that loosely depict some of the situations, characters, and relevant objects from the selected 360-scenario, but also present the user with additional context-specific items e.g. hearing aids, an FM-system (the wireless device that helps enhance hearing aids), and other items. The user can interact with the elements by dragging them around on the canvas, adding new items from the menu, or removing them. Additionally, the system also includes a drawing function, which allows the user to draw missing objects, characters or other

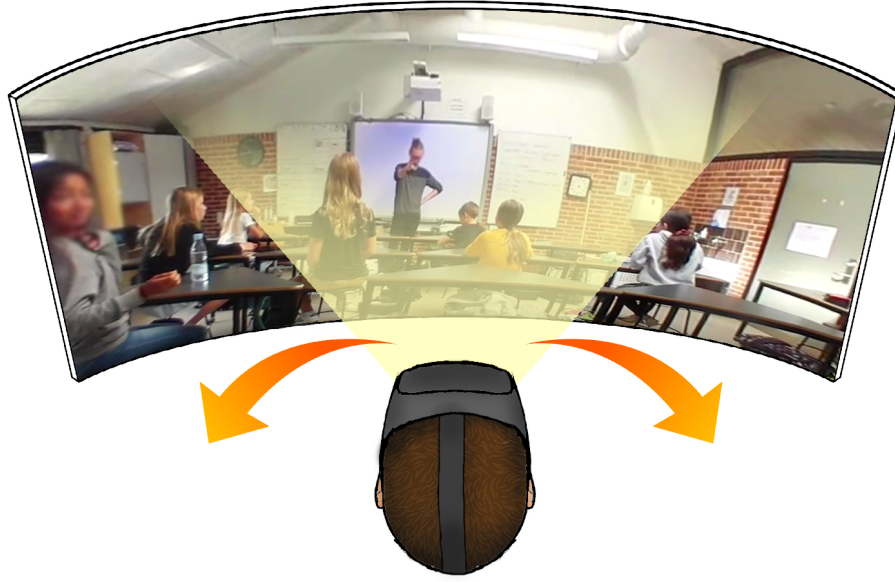


Fig. 3. Screen capture of one the 360-degree video scenarios, the school environment.

desired elements to support their narratives. Lastly, the system also features a ‘tips’ section, providing the user(s) with questions, suggestions and discussion topics for conversation scaffolding during the activity. After the activity the user(s) can save their creation and are awarded with a “thank you” animation.

3.2 Counseling Stages

The counseling stages for the specialist include: (1) the exploratory stage (2) the immersive stage (3) the reflection, strategy, and decision-making stage. In order to support structuring the session in accordance with the embedded goals, the tool comes with an additional tool guide. The tool guide acts as a supporting guide for the professional to navigate the system and provides suggestions for conversation scaffolding during each stage. The suggestions for conversation scaffolding [2] draw inspiration from the Ida Institute tools [22] [19], and narrative scaffolding conversation maps for supporting externalizing, deconstruction, and unique outcomes, as adapted by [34], [35], originally based on Vygotsky’s seminal work [31], [32].

The flow of the three stages go as follows: (1) In the *exploratory stage*, the specialist and the child can explore the impacts and potential challenges in the three communication environments presented, through the initially introduced narrative elements (context, characters, setting), and the interactive tasks and questions. By the end of the exploratory stage, the child’s responses to the questions will be displayed, and the specialist can further examine them: identify

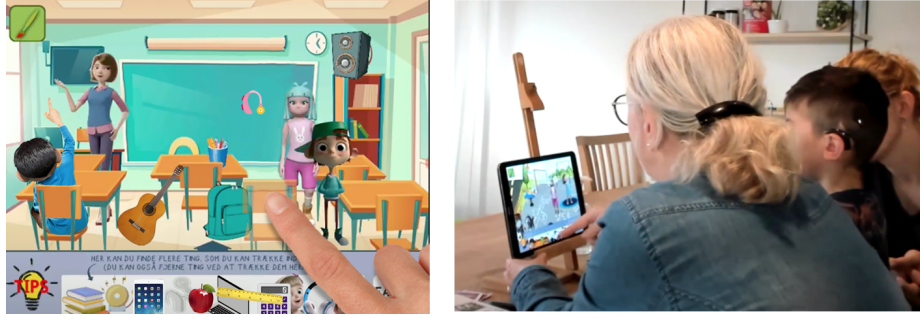


Fig. 4. Play activity on the tablet computer. On the left, screen capture of the play activity, school environment. On the right, specialist, child and parent engaging in the play activity, playground.

discrepancies, potential ambivalence and attitudes relating to the different communication environments. Thereafter, the specialist and the child can select a communication environment they would like to discuss and explore further.

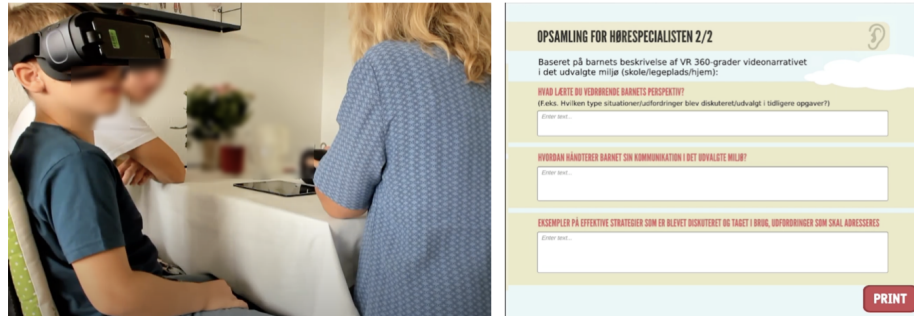


Fig. 5. On the left, participant exploring one of the VR scenarios, specialist and parent observing what the child sees on the tablet. On the right, form for the specialist to fill in comments and observations from the session.

(2) In the second, *immersive stage*, the specialist can make use of the VR feature. While the child is experiencing the 360-degree video in VR, the specialist and the parent(s) can see on the tablet what the child sees in VR (See Fig.5.). The specialist can use the suggestions in the tool guide to guide the child in the environment, or let the child experience it more on their own. In combination with the previous stage, the immersive stage serves as the foundation for the subsequent stage, helping to establish a common narrative communication platform.

(3) During the *reflection, strategy and decision-making stage*, the objective is

to involve the child in the collaborative problem-solving and strategy-building process through play and emergent storytelling (becoming a ‘co-expert’). Later in the process, the child’s creation from the activity can be saved and shared with the child and the parent(s), providing a type of a hand-out, or take-home resource. The system also allows saving the child’s responses, and provides the specialist a post-session form for filling in comments and observations from the session (see Fig.5.). This documentation and the hand-out can be used during follow-up sessions, for instance, as a conversation starter for discussing progress and strategies.

4 Evaluation

In order to develop a more in-depth understanding and assess potential benefits and limitations of this type of solution as part of a real-life pediatric hearing care setting, we conducted three case studies in which the tool was tested with 3 different HI-children 5-9 years old (Participant A 9 y/o, Participant B 5 y/o, and Participant C 5 y/o), by two speech- and language specialists (Specialist A and Specialist B). The chosen research methodology was an exploratory multiple-case study, in which the primary unit of analysis was the specialist-child couple. Both participating specialists had over 20-years of experience in the field of pediatric speech and language therapy. The three children participating in the study were all diagnosed with moderate to severe hearing loss and were all fitted with auditory devices.

The purpose of the evaluation can be considered threefold. Firstly, we were interested in knowing to what extent the tool, which integrates methods from narrative and play therapy into the proposed transmedia narrative framework, supports facilitating child-centric communication during the session. Secondly, we aimed to establish how the embedded structure of the system supports the professional in fulfilling the counseling-goals. Lastly, we were interested in investigating the feasibility and usability of such a tool, when used as part of real-life pediatric hearing care appointments.

Prior to the tests, we obtained informed consent from all participants of the study. It was agreed prior to the testing sessions that the tests would take place in environments that would feel familiar and safe for the children. Before each session, the specialist was introduced to the procedure, handed a physical tool guide, and given an overview on how to use the equipment. Granted the permission by the child, parents and the specialist, each session was filmed for subsequent video analysis. After each session, a semi-structured interview was conducted with the specialist. The qualitative data from the individual cases was gathered using a combination of qualitative data collection methods including direct-observation, video and audio recordings, unstructured pre-test interviews, and pre-test questionnaires, and post-test semi-structured interviews.

The analysis of the data is based on three primary areas of investigation: (1) the tool as a platform for effective communication, (2) effectiveness relating to the counseling goals, and (3) feasibility and usability. As the aim was to study each

case firstly individually and then together to establish similarities, differences, and patterns across all three cases, we used a cross-case synthesis to synthesize evidence from these multiple cases [28]. As the last step in the analysis we involved a pediatric hearing care specialist as part of our *participatory analysis* approach.

The equipment used during all testing sessions included two Samsung Galaxy tablets, one Samsung S8 smartphone, a Samsung Gear VR head-mounted-display (HMD), and an external Wonderboom Bluetooth speaker. One of the Samsung tablets was used for the tablet-app and the second one was used to mirror the Samsung S8 smartphone’s VR image during the VR experience, so the specialist and the parent(s) could follow what the child was seeing in VR. In case the child did not want to pair their hearing device(s) to the smartphone, an external Bluetooth speaker was used to amplify the sound during the VR experience.

4.1 Results

In all three cases, the tool supported uncovering essential information about the functional impacts of the children’s hearing loss and served as an effective springboard for facilitating communication during the sessions. Introducing digital technology as part of the appointment, particularly the VR headset, helped engage the children and the parents from the start. Moreover, as all participants had previous experience with using tablet computers at home, adopting the tablet app felt intuitive for all the children.

During the first stage, both specialists used the character and the subsequent interactive tasks and questions to elicit conversation on important themes and issues relating to the three presented communication environments. However, it was especially with the younger children, Participant B and Participant C, that important information emerged in this phase. For example, when discussing Participant B’s kindergarten environment, it was brought up by Participant B that he does not hear very well in the play-hut when other children are speaking. Participant B’s mother then supported the specialist in further exploring this issue by asking, “Do you hear some of what they [the other children] are saying?” to which Participant B replied, “I do not hear anything at all.” While with Participant C, it emerged that he was highly sensitive to the noise of slamming doors and the noise of rain falling when at the kindergarten.

The narrative framework embedded in the tool, partially relying on the 360-video VR scenarios, was observed as most effective with the older participant (Participant A, 9 y/o). In this case, it supported the child in sharing his perspective and helped the specialist in introducing new strategies. During the play activity, reflecting on the VR scenario to help the character cope better in the selected environment, Participant A selected the same type of hearing equipment and the same type of technology for the character as he himself had. When Participant A was asked why he gave the character an iPad, he replied that, it was so the character Sara would not have to focus on what was going on around her, and could get away from the surrounding noise. It was later suggested by the specialist that the child likely projected his own coping-strategies and perspectives on

the character. This gave the specialist an opportunity to better understand the child’s perspective and identify previously unknown issues. The specialist also used the narrative platform to introduce new strategies in a way that did not directly involve the child, “Sara is 9 years old. And she just got the phone. Does she know how to hold it so that she can hear better?” The fact that Participant A felt it was more of a game where he could also be the expert, encouraged him to participate in the strategy-building and decision-making process more actively, while allowing the specialist to steer the conversation naturally to the child’s own habits. Specialist 1 assessed the role of the VR feature in establishing the narrative communication platform with Participant 1 as an essential part of the tool, “It was something he was captivated by. When he gets captivated by it, we can then also talk about it. Had he [Participant A] thought it was too boring or had not liked it, we also would not have been able to talk about it later.” In this case, not only did the VR feature help make the session more exciting and engaging for the Participant A, but it also had direct implications for helping facilitate the conversation during the later phases.

On the other hand, in the case of Participant B and Participant C, the narrative framework did not work as well as intended. It was clear that both younger participants found it difficult to apprehend the VR experience, subsequently making it more challenging in terms of bridging the experience with the latter play activity on the tablet. Although both enjoyed exploring the functionalities of the system, they also needed much more support from the specialist in terms of contextualizing the play activity based on the previously presented information. Furthermore, despite the suggestions provided in the tool guide, and both specialists seeing the VR feature as a valuable addition to the tool, it was also clear that the specialists were new to this type of technology, and found it challenging to put to use in terms of serving the goals of the session. Therefore, to encourage further exploration, and for the VR experience not to become underutilized during the session, this feature would require either an instructional debriefing, or some other type of an embedded protocol for the specialist.

Nevertheless, the findings suggest that the tool offered a structured and time-framed approach for the specialists to explore the various impacts of the children’s hearing loss. And while the tool was demonstrated as most effective for exploring the functional impacts, it was evident that it also provided ways for scaffolding psycho-social impacts. Both participating specialists were interested in adopting the tool in their practice.

5 Conclusion

The present study was designed to explore the possibilities and potential of a narrative transmedia counseling tool that integrates smartphone-based VR for encouraging a more child-centered approach during pediatric hearing care appointments. The communication tool was based on a transmedia-based emergent narrative system, and was directly tied to the counseling goals, integrating methods from narrative and play therapy. The tool was evaluated through three case

studies in which two speech- and language specialists tested the tool with three children diagnosed with hearing loss. The findings suggest that the tool was most effective in supporting the specialists in exploring the functional impacts of the children's hearing loss, while allowing for scaffolding psycho-social impacts. In all cases, by establishing a communication platform based on context-specific themes and narrative elements, the tool provided a way for the children to actively engage in conversation about their individual perspectives, promoting the children's self-advocacy skills during the session.

While the novelty of the VR feature managed to equally engage all the participants, the younger participants found the experience more difficult to apprehend. Hence, the narrative communication platform integrating the VR feature, was more effective and beneficial when used with the older child. In this case, the narrative communication platform provided a way to better understand the child's perspective but also offered an additional way for the specialist to introduce and collaboratively define new strategies without putting unnecessary pressure on the child. Nevertheless, for the VR feature not to become underutilized during the session, it would require an instructional debriefing, or some other type of an embedded protocol for guiding the child in the VR environment.

In this study, the tool was tested by two speech and language specialists, who have different roles and approaches in the pediatric hearing care process, therefore, it could also be interesting to establish the potential of the tool in a more clinical context, for instance, when used as part of an audiological assessment. Moreover, future work should focus on providing more opportunities for personalization i.e. adding more characters, the children being able to themselves choose the character's gender, age, hearing equipment. While the narrative system was considered most successful when used with an older child, the different elements of the tool showed high potential with younger children. The fact that the specialists participating in the study were interested in adopting the tool into their practice, further demonstrates the potentiality of this type of a solution as part of a pediatric hearing care session for enhancing child and care provider communication.

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