A COLLABORATIVE APPROACH TO DIGITAL STORYTELLING IN HEALTHCARE SETTINGS

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ABSTRACT

Human-centred design in the healthcare setting can include patients' and families' perspectives when researching, designing, and developing interventions. There are multiple qualitative research methods that may be employed to collect user data. Naturalistic video recordings are a powerful means of observing and coding multiple participants and evaluating their interactions over time. However, in the healthcare space, researchers need to be especially intentional with use of video-based data, so the confidentiality of all participants is maintained. Digital storytelling can be used as an effective way to securely share the interaction and emotions directly from the videos so that the content can be disseminated with researchers, clinicians, participants, and policymakers. The goal of the digital stories is to authentically convey observed experiences to a broader audience, including as educational tools for healthcare team member training. This paper presents a collaborative approach to producing animated stories that can be used to promote discussion and action for clinical quality improvement, from our work with birthing parents, their companions, and their healthcare team members in a hospital-based postpartum unit. We describe various considerations related to digital storytelling for provocation, involving multi-disciplinary stakeholders in identifying priority scenarios, and the development process of digital stories. Considering the growing emphasis on patient-centred and equitable healthcare, our reflection may be useful to designers and researchers working with sensitive data, or healthcare educators and administrators seeking ways to build more empathy around human experiences and prompt discussions to improve systems of care.

Keywords: Design research, human-centred design in healthcare, digital storytelling, maternity

1 INTRODUCTION

Designers are increasingly active contributors in the healthcare sector. Design-based research, visualization, and prototyping methods can aid in reimagining systems of care [1],[2]. We are a team of designers and a medical anthropologist working across universities on a large, government agency funded research grant to improve systems of perinatal care. In this context, an interdisciplinary approach is important for generating new knowledge to advance understanding of stakeholder needs in the birthing facility and through postpartum discharge. The design team contributions include leadership with research approach, data collection, analysis, design, and the development of interventions. Through this collaboration, we are learning new ways of effectively conducting research. We are also exploring new applications of our skills, tools, and methods for impact. In this paper, we refer to our collaborators as the 'research partners' and refer to the designers in the multi-university team as the 'design team'.

Our research partner team has collected multi-method data including naturalistic videos of patients and families during their stay on a postnatal unit. Working with social scientists and clinicians, we have applied rigorous methods for qualitative analysis along with gaining an appreciation of the depth of information that is collected through extended observational and audio data. These videos document the raw, unfiltered emotions, reactions, and actions of what participants are experiencing over the course of their postnatal unit stay and care transition. The videos record instances of supportive care, as well as challenging encounters between patients, families, and members of the healthcare team. The recorded behaviours and soundscape provide valuable insight into experiences that are otherwise hard to document. These files could potentially be directly used for training and education of clinicians, however

there are many issues that prevent this application from being an appropriate solution [3],[4]. In the original video format, there is extensive personal identifying information. Furthermore, the length of the videos (even interactions that happen over a 5-minute window) would be too long for teaching purposes, which limited the scope of the video to coding, to identify the context and patterns. These limitations are opportunities for design. Using visualization and digital storytelling, designers can transform the content of the video and audio recordings to animated stories, to elicit empathy, and support stakeholder engagement and discussion in an appropriate and feasible manner.

In this paper, we share a collaborative approach to develop digital stories. The purpose was to provoke discussion amongst healthcare team members. We discuss details of our process with our research partners to identify priority interactions from the videos. We share how to develop digital stories that center the experiences and emotions of patients, while protecting the privacy of all participants. Additionally, we will summarize contributing factors to producing digital stories in the context of sensitive data. We believe this paper can be a resource for students and researchers who are interested in exploring digital stories as an approach to eliciting discussion around complex health-related topics, to improve care.

2 NATURALISTIC VIDEOS AND DIGITAL STORYTELLING

2.1 Naturalistic videos

There is a long-standing interest in using video ethnography and naturalistic videos as a method of observation and as a way of studying complex social and health-related settings [4],[5],[6]. Naturalistic video involves "the video recording or filming of the stream of activity of subjects or observation of real-life experiences in their natural setting, in order to experience, interpret, and represent behaviour" [7],[8]. In the setting of maternity care, Tully and colleagues have successfully conducted this type of research with postpartum families and healthcare team members, and their findings address patient safety and clinical efficiency [9],[10]. Digital storytelling builds on this line of work by illustrating the complexity in healthcare environments through highlighting behaviours, contexts, nonverbal cues or interactions, and environmental factors. The video data provide insight into the nuanced dynamics of clinical encounters, and, critically, into the emotions and reactions of patients and their companions after healthcare members are no longer in the clinical space. This information can help identify the needs and challenges of patients' experiences, by offering examples of positive interactions between healthcare professionals and patients [11] as well as opportunities for improvement. Practically, participants could consent to naturalistic videos being used as educational material for training healthcare professionals or clinicians [3]. However, that approach would come with challenges. These videos contain sensitive and confidential information. Asking for participant consent to share with those identifiers outside of the study may limit enrolment, affect the extent of participation (turning recordings off/on), and introduce more complexity for ethical management [12]. Additionally, it can be difficult to isolate the information and convey certain aspects of the recorded experience or behaviours to the audiences in a de-identified image or other snippet without distorting the story or striping the event from the fuller context. Meanwhile, traditional formats for sharing qualitative data findings such as written reports or presentations may remove the empathic pieces and fail to convey the critical emotional components or contextual information with the viewers [13].

2.2 Digital storytelling

Digital stories are described as "short visual narratives (approximately 3- to 5-min) that combine and synthesize images, video, audio recordings of voice and music, and text to create engaging and compelling accounts of experience" [14]. This method of conveying information is gaining popularity in healthcare and is used as an educational and health promotion tool for sharing culturally relevant and respectful information and messages [15]. Digital stories and narrative-based videos have been used for various education and behaviour change related purposes around maternity care such as stress management, weight management, or promoting physical activity and healthy lifestyle [13].

2.3 Our study

Following review by the UNC Chapel Hill Biomedical Institutional Review Board (#19-1900), this study involved multiple methods of data collection including 461 hours of naturalistic videos among 15 postpartum patients and their companions in an academic medical center in the south-eastern United States. These videos averaged 31 hours (range 10 to 76) from two camera views in the participants'

postpartum unit rooms. To date, twelve hours of videos recorded from each participant prior to their discharge were analysed. The design team, along with research partners, participated in reviewing and analysing these videos to organize the vast amount of data, cluster codes, and develop further understanding of the context. The purpose of this analysis was to disseminate findings from selected interactions as part of identifying opportunities for improvement. The process of analysing and identifying the emerging themes from videos followed multiple iterative steps including reviewing and coding the videos in 5-minute increments with a behavioural taxonomy, identifying emerging themes, and creating detailed vignettes. Vignettes in this context were summarized accounts of events, participants, situations, and structures, which made it possible to refer to important points in the study of behaviours, perceptions, and attitudes in the context [16]. The vignettes were structured to address the timeframe, environmental factors, interactions between people present in the scene and the documents included memos from the design team and research partners for in-depth understanding of the participants' behaviours or the context. The primary purpose of the video data collection and coding was to generate findings to identify the patterns of behaviour and topics addressed, disaggregated by birthing parent ethnicity-race, to inform systems change and implementation for patient safety. The design team also explored opportunities to use the data for building empathy and engaging healthcare team members as experts on the subject in the education and discussion around possible areas of improvement and reflection. Hence, the design team was aiming to provide healthcare professionals with tools or options that would enable them to ask questions about patients' experiences, share in-depth insights into the root causes of the issues such as communication problems or biased care, and offer feasible solutions to some of the existing gaps. To move from using images from videos to communicate key moments in stories, which cannot fully convey the details or emotional atmosphere of the interactions, the design team condensed the high volume of content and details into organized, digital stories (Figure 1).
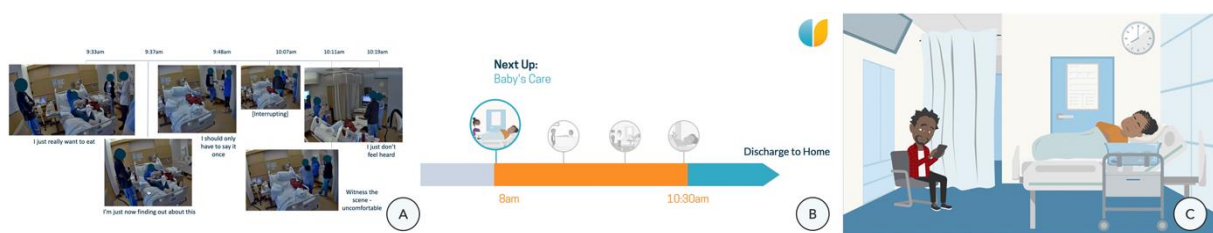

Figure 1. Use of de-identified images selected from video data (A); Use of animations with more comprehensive accounts of events from the video data (B); Digital image from the animation, with characteristics retained from the video data (C)

3   DIGITAL STORYTELLING FOR PROVOCATION

Given the rich datasets generated from naturalistic filming, we believe that digital stories are an appropriate method to convey key elements, with important contextual and emotional elements. Further, digital storytelling can be an effective method to shift power dynamics in research. Creating shareable accounts of participants' experiences protects confidentiality and may promote the agency of stakeholders. By transforming the data into shareable visualizations, such as digital stories, participants can see that their stories are heard, verified, and represented [14], [17]. Digital storytelling can engage study participants and other stakeholders around their lived experiences. Using digital stories as a provocative and tangible artifact for discussion in this context invites people to think, question, and re-evaluate the current reality around postpartum care [18]. Provocative design challenges the status quo and stimulates discussion. In this sense, "asking questions is as important as solving a problem" [19]. As such, asking prompting questions at the end of animated stories can enable discussion around gaps in care or opportunity areas for systems improvement. Also, digital stories as provocative tools allow the 'researcher' to select a perspective on a scene, emphasize on an experience, or zoom in and out on specific details of a situation observed and control the narrative. Multidisciplinary, diverse teams are therefore essential for determining the appropriate focus and messaging.

4   DEVELOPING DIGITAL STORIES IN THE POSTNATAL UNIT

Our team took a collaborative approach to develop digital stories that accurately depicted examples or real situations. Clinicians and other research partners identified priority interactions from the video and

audio data, for the design team to build digital stories that could elicit conversations and discussions among healthcare professionals. We reflected on several questions through the process of making each iteration of the digital stories. These were as follows:

1. How can storytelling and digital stories elicit conversation and enable healthcare professionals to engage in a discussion around system strengths and opportunity areas?
2. How can we emphasize specific dimensions of the interaction, experience, or setting to bring attention to one issue at a time?
3. How can we leverage the richness of the naturalistic videos to share stories of/from the postnatal unit while protecting participants' confidentiality?
4. What are the best practices and technical considerations for creating narratives that are engaging while the context, behaviours, and dialogue are kept intact?

To address these questions and create actionable digital stories we followed specific steps, including (1) defining the scope, (2) shaping the style, and (3) technical considerations.

4.1 Defining the scope

To identify the appropriate examples, in collaboration with our research partners, we had to decide what sections of the original videos could provide the most valuable insights from the birthing parent and companion perspectives. Together, we prioritized the content. To facilitate this process, the design team developed a worksheet that allowed the research partners to select and summarize sections of the video and note examples that they felt were worth discussing with the healthcare community around the topics of communication, language barriers, racial impact, and pain management. Using the worksheets and by referring to the vignettes, the design team and research partners collaboratively defined a specific objective for each digital story. Some of the prompts used in the worksheets for the research partners to identify effective examples from the original videos and subsequently craft a message were as follows:

- Share some details about what happens in your chosen story (include any important actions, quotes, or sounds that are most descriptive or stand out; include IDs and time window)
- What is the goal of the digital story?
- What is the main message of the digital story?
- What background information does the viewer need to know?

The design team used the information from worksheets plus the vignettes to develop the animated videos. The process remained iterative because of the level of complexity in framing the context and finding the appropriate balance with the details to include in the digital stories. In some cases, this meant simplifying the story by removing some details while maintaining our interpretation of its essence. For example, replicating the exact conversation from a scene in the video without clarifying the context could have been confusing to the viewers or affected the accuracy of the information. Additionally, providing too much information or presenting a long video could overwhelm the viewers and distract them from understanding the main points. Thus, we strove to reduce the content we determined to be tangential to enable the viewers to focus on a certain topic. Additionally, we decided to use a narrator to present a short overview of the setting and context at the beginning of the story. The narrator approach was also included at the end to introduce questions - to invite the audience to reflect and engage around the problem/experiences depicted in the digital stories.

4.2 Shaping the style

Two main considerations in shaping the visual style of the digital stories were the design of environment and maintaining concordance with characters' appearance, mannerisms, and voices. In designing the environment, we initially aimed to depict the setting in a precise manner but ultimately opted for a comparatively simplified or 'minimal' style to emphasize the characters and their interactions (Figure 2). Additionally, we wanted to ensure that the appearance and sound of characters in the digital stories appropriately represented the study participants, including with their skin tones, body shapes, and clothing styles. Similarly, for the voice-overs to use in the digital stories, we recruited our research partners who shared racial/ethnic characteristics with the story characters. We asked them to review the original footage before participating in the voice-over recording sessions, to promote their understanding of the emotional context, tone, and feeling of the conversations, and record the dialogues that were adapted from transcriptions of the audio with attention to the original event and experiences.

Figure 2. De-identified video footage (A); precise style of the environment (B); final minimalistic environment (C)

4.3 Technical considerations

Having the right tools and technologies to develop the digital stories also plays an important role in the development process. Producing high-quality digital stories can be time-intensive and the software can also be expensive. The designers leading development of the digital stories did not have prior experience in making animations or digital stories. Hence, there were two main considerations for the choice of the software: the ease of use and possibility of collaboration. We compared potential software such as Adobe Premier [20], Adobe After-Effects [20], and selected an online animation software Vyond [21]. Vyond allowed the designers to work collaboratively, had a short learning curve, and did not need learning complex editing features. This platform had a series of built-in visual styles, flexible settings and features for character design such as pre-set actions or expressions that allowed us to produce the digital stories efficiently. Also, these features helped us maintain the ethnic, cultural, and physical features of the participants. Using this platform, we were also able to create a library of visual assets which reduced the production time, particularly as we scaled our production to create multiple videos sharing common assets.

5   REFLECTION AND DISCUSSION

The process of developing digital stories to depict highlights of naturalistic videos proved to be more complex than we initially anticipated. As we moved through an iterative process, maintaining the integrity of the original story was challenging and time-consuming. We balanced being precise with documented the participant experiences with adapting for useful/effective stories as standalone artefacts. Despite the challenges, our iterative production process in collaboration with the research partners, proved to be successful in ensuring the digital stories aligned with our goal to have discussions around interactions, communication, and safety during maternity care, as part of integrated work towards our project's overarching goal of improving maternal and infant safety.

We designed these videos for the specific context of health and maternity care. However, insights from our process can be transferred to other settings where researchers work with sensitive health-related data or work towards provoking discussion around complex topics. We suggest the following guidelines that other teams may benefit from considering:

- Defining the overarching purpose, message, and storytelling prompts
- Engaging relevant stakeholders during the development process
- Analysing the data and prioritizing the most important themes
- Reducing complexity by keeping the most essential or focal elements of the story
- Understanding the resources and available technologies (video and audio)
- Defining the style to emphasize essential elements of the story
- Developing prototypes to test the storyline and visual elements
- Maintaining flexibility and remaining open to feedback
- Following an iterative process to refine the digital stories

While our goal of designing and developing these videos was to initiate discussion among healthcare professionals and providers, we also presented versions of the digital stories to the general public through exhibition opportunities – this is another avenue for us to provoke discussion and motivate action around the problems surrounding systems of postpartum care. We acknowledge there is a need for testing and evaluating the digital stories we produced, for their effectiveness as meaningful materials to facilitate discussions among healthcare team members – this would enable us to further refine our process in developing the digital stories. Considering the time-consuming production process, we anticipate additional limitations and challenges in scaling production to create digital stories

representing the large range of problems and experiences in our focus area, beyond those we have addressed in the digital stories so far.

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