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Participatory video analysis in disability research

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This article sets out critical framing as an analytical approach in participatory video by which people investigate and analyze a topic through arts-based engagement, storyboarding, and collaborative editing. Participatory video as an action research method in self-advocacy has been discussed elsewhere. Here, the author examines critical framing and the role of generative themes in participatory analysis by describing a case study in which adults with developmental disabilities explored the dimensions of sexual health through participatory video. The author proposes that critical framing provides a more nuanced approach to participatory analysis. Credibility and trustworthiness with data triangulation and overall findings are also described.

Keywords: participatory video; disability research; participatory analysis; participatory visual media; critical framing; sexual health

Points of interest

- Participatory video involves a group of people creating videos about a topic or issue that is important to them.
- This research is about a group of adults with developmental disabilities making participatory videos about sexual health.
- This study describes critical framing, a type of analysis in which participants are actively involved in the research process. This included arts-based exercises, storyboarding, and editing.
- This approach to analysis also opens up spaces to learn from each other through storytelling and sharing experiences. Participants are also involved in making decisions about the research.

Introduction

This article sets out critical framing as an analytical approach in participatory video by which people investigate and analyze a topic through the interconnected processes of arts-based engagement, storyboarding, and collaborative editing. Here, the author examines critical framing and the role of generative themes in participatory analysis by describing a case study in which adults with developmental disabilities explored the dimensions of sexual health through participatory video. Participants

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investigated this topic by developing and filming short videos, conducting interviews on and off screen, analyzing themes in collaborative editing, and distributing the final videos as a form of knowledge translation about sexual health and self-advocacy. The author proposes that critical framing provides a more nuanced approach to participatory analysis. Credibility and trustworthiness with data triangulation and overall findings are also described in relation to collaborative and participatory visual research.

Participatory video

Over the last 15 years there has been growing interest in participatory video as a research methodology in disability research (Ignagni and Church 2008; Manning 2010; Okahashi 1998, 2000; Sitter 2012). What differentiates participatory video from other visual genres is the process: participatory video involves community members creating videos in a group setting about a topic or issue of concern (Shaw and Robertson 1997). Through various activities, participants take on the role of ‘co-filmmakers’ and familiarize themselves with the technology, create storyboards, and work through processes of collaboratively developing videos. White also describes the process as transformative:

[Participatory video] can serve as a powerful force for people to see themselves in relation to the community and become conscientized about personal and community needs. It brings together critical awareness that forms the foundation for creativity and communication. Thus, it has the potential to bring about personal, social, political and cultural change. (2003, 64)

The origins of participatory video are traced to Fogo Island, Canada in the 1960s, where it grew out of a community partnership with the National Film Board that involved Islanders creating short films about life on Fogo (Crocker 2003). The collaborative nature of filming differentiated itself from other genres during this period, as ‘subjects’ of the film participated in the creative process of development. This approach drew on principles of collaboration, community organization, and de-centering the notion of ‘expert’.

More recently, participatory video has been applied as a research methodology in disability research (Ignagni and Church 2008; Okahashi 1998, 2000). The use of video enables people to explore, debate, and honor their own knowledge and experiences. Critical aspects to the research process are accessibility and inclusion. For instance, Okahashi (1998, 2000) described a participatory action research study in which people with developmental disabilities created videos on the topic of human rights in order to increase accessibility for a wider audience. The author discussed the use of participatory video in documenting histories and sharing stories, which can build connections within the community when publically screened (Okahashi 2000). According to Okahashi, part of the potential for using participatory video with persons with developmental disabilities is accessibility: ‘When the printed word is less accessible, video promises a different literacy’ (2000, para. 13).

Participatory analysis in the participatory video process

As collaboration is a core element of participatory video, considerations are needed with how to approach participatory analysis (Sawhney 2012). Labacher et al. (2012)

identified storyboarding as a method of participant analysis within a participatory video project on gender and poverty reduction in Rwanda. During this process, participants produced a series of storyboards that constituted visual data which assisted in: identifying the problem or topic of inquiry; story resolution; and ownership and engagement with the topic (Labacher et al. 2012, 159–160).

In contrast, other studies have focused on editing as the main approach to participatory analysis: Haw and Hadfield (2011) described an analytic process in which both the researcher and the participants jointly analyze video content. Similarly, Sawhney (2012) explored a peer-based approach to editing that emphasized participant interaction, in which analysis is conducted through informal, peer-based conversations with participants. Sawhney's approach to collaborative editing focused on critical reflection amongst participants while simultaneously working on overall video quality.

While participatory video analysis is a relatively understudied area, the limited scholarship indicates varying approaches regarding participant involvement where there is an insufficient understanding of how participatory analysis can be conceptualized within the overall participatory video process, not merely a sub-section within the methodology. To address this issue, this article sets out an analytical approach to participatory analysis. Referring to this approach as 'critical framing,' this form of participatory analysis takes into account the transitive function of participatory video by considering how a series of interrelated processes – topic development, storyboards, and editing – contribute to investigating the topic. The approach is examined in more detail through a case study where adults with developmental disabilities explored the dimensions of sexual health using participatory video.

Methodological context

According to Hingsburger (1995, 2006), sex and sexuality for disabled people are taboo topics in many spaces. Persons with disabilities often lack resources, information, services, and support in areas of developing and maintaining positive, healthy relationships (Crawford and Ostrove 2003). Research studies have also found that high rates of poverty, segregated institutions, silent histories, cultural values, and social stereotypes have a critical role in sustaining barriers to sexual rights for adults with developmental disabilities (Gill 1996; Kelly, Crowley, and Hamilton 2009; Pan and Ye 2011; World Health Organization 2011).

This article describes the participatory analysis process that came out of a larger 12-month research study in western Canada in which a group of self-advocates explored the topic of sexual health by developing and filming a series of short videos that represented various dimensions and experiences of sexual health in the disability community.¹ Participants subsequently distributed the final videos as a form of knowledge translation about sexual health and self-advocacy.

Recruitment for this study occurred through a community group entitled 'Right to Love.' As a temporarily able-bodied university researcher, the author had community connections with this disability organization through several community-based filming projects and events. The author approached the Right to Love group to discuss the potential of a participatory video project. Ethical approval to conduct this research was obtained through the author's affiliated university. A total of nine adults with developmental disabilities and three allies participated in the study.

Members who participated in the study signed consent forms and had the option of choosing a pseudonym.

While the overall study explored participatory video in the context of social change regarding process, content, and self-advocacy, this article focuses on process, with consideration to the following questions: ‘How can participatory analysis be taken up in the participatory video process?’ and ‘What are the ways in which data can be analyzed, interpreted, and discussed with consideration to the theoretical framework guiding the research?’

For the first four months of the study, two-hour meetings occurred approximately twice a month, followed by monthly meetings. Both the filming and the community presentations occurred outside these meetings. In tandem with the participatory analysis phases, the researcher employed a reflexive positionality in order to interpret processes of visual engagement within the broader context of the overall theoretical framework (Guillemin and Drew 2010; Stanczak 2007). Data included meeting notes, artistic montages, storyboarding, raw and final footage, field notes, and reflexive journaling. All meetings were audio-recorded and transcribed.

Action research

This action research study was guided by Freirean theory and a critical disability orientation. Action research emphasizes participation, critical reflection, and emancipatory praxis. Freirean theory guided the overall approach and is the underlying philosophy of participatory video (White 2003). Freire stressed that a person’s own knowledge is valuable in the process of social change, and placed an emphasis on meaningful involvement (Freire [1970] 2008). Biklen describes how critical disability is informed by lived experiences:

The term ‘critical’ refers to those works that recognize disability as a social construct and which see disability as occurring within shifting political, economic and social contexts, often highly marginalizing and discriminatory in nature ... These are the works that seek to redefine the meanings of disability and to foster participation of people with disabilities in the exercise of power. (2000, 337)

This position rejects the role of people with disabilities as objects of study, and acknowledges that people have the right to be consulted and involved in research which affects their lives (Chappell, Goodley, and Lawthom 2001; Gilbert 2004).

Critical framing: participatory analysis

Critical framing involves participants leading the process of identifying and exploring generative themes through arts-based activities, storyboarding, and editing, where the final videos are representations of the various themes identified and analyzed by participants. Generative themes are based on Freirean theory, which is a guiding theory in participatory video and is a critical aspect to this analytic process. Herr and Anderson (2005) define generative themes as identifying issues and topics that are agreed upon by community members which have the highest priority. According to Freire:

To investigate the generative theme is to investigate people’s thinking about reality, and people’s action upon reality, which is their praxis ... The more active an attitude men and women take in regard to their exploration of their thematics, the more they

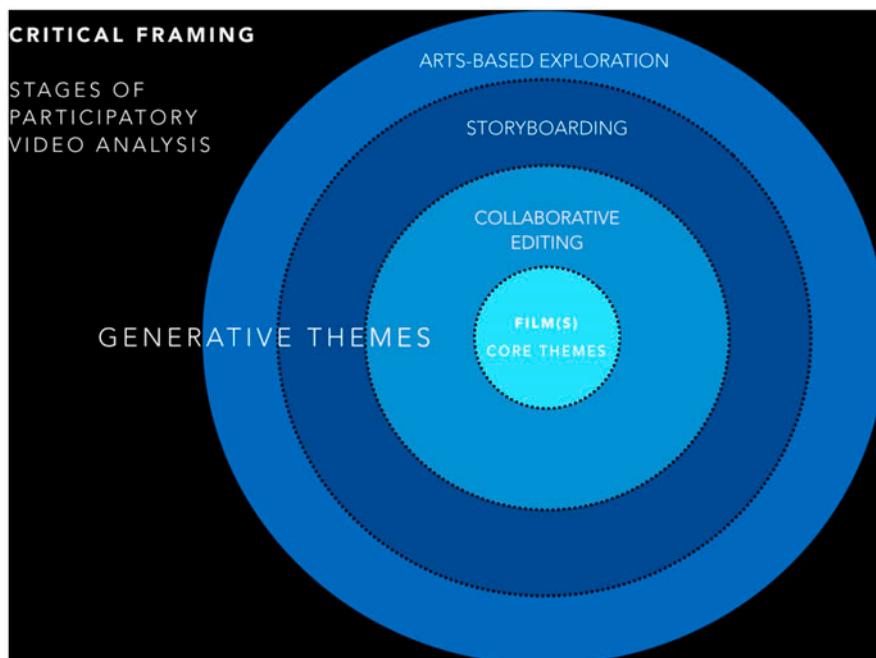


Figure 1. Critical framing. This image represents the process of critical framing and generative themes applied to participatory video analysis.

deepen their critical awareness of reality and, in spelling out those thematics, take possession of that reality. ([1970] 2008, 106)

Generative themes unfold into other themes and can be visually thought of as concentric circles, moving from the general to the particular (Freire [1970] 2008, 103). The critical framing process is exemplified when exploring generative themes through three phases – arts-based exploration, storyboarding, and collaborative editing – where participatory analysis begins on the outmost circle, broadly exploring the topic through arts-based exercises (see Figure 1). The following sections describe these phases in further detail and how participants identified, investigated, and interpreted generative themes associated with sexual health and disablement. Considerations regarding practical techniques are also identified to provide a more nuanced understanding of participatory analysis in the overall methodology.

Phase 1: arts-based exploration

In this case study, the first stage of participatory analysis involved arts-based exploration. This required exploring practical techniques to ensure people with different levels of ability had an opportunity to participate in the research process and express themselves in ways that were most comfortable to them. In investigating the overall focus of the videos, we engaged in creative forms of expression in order to represent different perspectives associated with sexual health. These exercises were guided by a series of questions to: develop the goals of the research; identify filming ideas; and establish distribution channels.

Reflexivity was encouraged through a series of questions. At the beginning of the first activity, the following question was posed to the group: ‘What does the “Right to Love” mean to you?’ We used magazine pictures, poetry, drawings, and stickers to create individual artistic pieces to express thoughts and experiences about sexual health (see Figure 2). We shared our pieces with each other, and subsequently combined our different pieces on a large poster paper located on the wall to develop



Figure 2. Arts-based engagement in participatory video.

a montage. During this activity, individuals continued to share what the montage of visual imagery represented to them.

This iterative process led to sharing personal stories around lived experiences and evolved into another creative activity guided by the question ‘What do you want to tell people about your story?’ Participants responded by identifying areas of focus within their stories, while also raising other questions associated with disability and sexual rights. In one of the final exercises, the following question around distribution was posed: ‘Who needs to see the film(s)?’ People drew pictures of caregivers, friends, family members, and politicians and talked about why they these people need to know about their stories.

A series of generative themes evolved out of these arts-based activities. In this process, the act of people sharing filming ideas, discussing their different experiences around sexual rights, and identifying key audience members enacted the initial stages of participants co-investigating issues central to their lives around the topics of love and relationships. The identified themes also provided initial filming topics that would be further explored in the storyboard process: love is a critical human rights issue for the disability community; the role of self-advocacy in our sexual health; histories of services that supported love in the disability community; barriers to sexual rights; needed supports; relationships and sexual orientations; and honoring life stories and personal experiences.

Phase 2: the storyboard process

Storyboarding is considered an integral part to participatory video (Labacher et al. 2012). Most often, a storyboard can be created on a piece of paper or other digital programs where participants make notes about each shot and draw rough sketches for a collection of frames. As a tool, participants can also use storyboarding as a planning device for making and discussing a video production in relation to its focus (Labacher et al. 2012).

In our research study, a storyboard was developed based on the generative themes identified through the first phase of critical framing. A large poster paper was placed on the wall that captured the various themes. While there were practical reasons for using a storyboard, it also served as method of analysis. The process was valuable in that it provided the basis to begin exploring the generative themes in more depth while deciding on the most appropriate filming genre. Participants decided on a documentary-style approach in which they could conduct interviews with each other and community members. These decisions led to logistical discussions about the filming process, which was subsequently captured on the storyboard. This included who to interview, the types of questions to ask, who would do the filming, and the different responsibilities in coordinating each shoot.

The storyboard worked as a series of branches to go in different directions, and was a living document throughout the editing phase of our research. For instance, in the one thematic area of relationships, participants immediately started naming guardians, and people with disabilities that have married, have children, and also identify with the LGBTTQ (Lesbian, Gay, Bisexual, Transgender, Two-Spirited, and Queer) community. During this process, we discussed the reasons why there was an interest in interviewing certain people and how this builds on the focus of the films.

Identifying people to interview proceeded with developing potential questions, which occupied most of our storyboard meetings. Through our discussions we

created two lists: questions that participants wanted to ask of every interviewee (e.g. ‘What does the “Right to Love” mean to you?’) as well as specific questions that circled back to the identified theme.

Exploring visual representations of themes also occurred during the storyboard process. When working through sequencing of shots, participants identified different still and moving images to represent various themes. For instance, to visually depict advocacy, participants proposed filming at an upcoming activist event; to communicate collaboration and unity, participants decided to include still images of their community events; and to demonstrate pride and celebration, participants decided to film community members at the annual disability pride parade.

Human agency also echoed throughout various spaces in the storyboard process, which afforded the participants with a level of authority and decision-making power. As explained by one participant: ‘We’re the people who decide what the film is gonna be about, and then we decide if we want to invite more people, and if we want to interview more people to tell their stories.’

Phase 3: collaborative editing

The editing phase occurred over three months. During post-production, the raw footage was reviewed at the scheduled meetings. Although time intensive, this approach provided opportunities to discuss the video clips in more detail. Owing to the number of participants, video clips were displayed on a large screen in the meeting room.

The final videos are representations of the various themes identified and analyzed by the participants during the editing stages. Editing involved an interrogation of these themes through the cyclical process of viewing–discussion–reflection–action. This emic analysis served to identify sub-themes within each of the generative themes. Questions that guided the overall approach to the process can be communicated through the acronym LENS: how do these clips *Link* to cultural, political, and historical contexts about our sexual rights; how do these clips relate to our *Experiences*; what is *Not in the frame*, but important to know when watching this video; and what *Silenced histories* are being shared?

Freire ([1970] 2008) states that when people are looking at the thematic investigation, part of the analysis that is required is to recognize the interaction of the various components. By recognizing how they interact with one another, there is a critical analysis that unfolds and a new way in which people understand their reality in more depth – which then begins to introduce people to a critical form of thinking about their world and their reality (Freire [1970] 2008).

The process of collaborative editing provided greater visibility to a person’s situation and enacted Freirean theory of generative themes. In watching the video clips, participants began to further identify connections between video interviews and their own experiences while concomitantly connecting the video clips to the topic of sexual health. For instance, participants viewed Dennis’ interview about his experience in an unhealthy relationship, where several participants found a connection in his story to their own experiences:

- Joan: I like, when you said you choose this woman and you thought it was good and that she didn’t turn out so good. Because sometimes we choose the wrong people.
- Dennis: I know, I know. We make mistakes, we make mistakes.

Joan: I can relate a lot to your story.
 Thomas: So can I.
 Mary: There are a lot of differences, but there are a lot of similarities in our stories too.

In this example, participants explained that the right to make mistakes is something which is rarely afforded to people with disabilities, especially in the context of sexual rights; several participants indicated that parents, caregivers, and members of their social networks who hold positions of power often forget that making mistakes is part of being a person. Throughout the study, participants shared examples of how different people in their lives provide them with information on sexuality while also being extremely influential in supporting – as well as hindering – their sexual rights. Based on these discussions, participants decided to include the following statement in one of the videos to communicate this core theme associated with barriers: ‘The law aside, caregivers, parents, and guardians hold a lot of power’ (Barriers video).

The editing process was iterative, where the group would continuously explore each of the themes based on each other’s feedback and understanding. Although the storyboard was used as a guide for the filming process, the sequences often changed after the participants viewed the clips and other themes began to emerge. For instance, the topic of support and sexual health was an identified theme, but in the editing process participants discussed the complexity of supports beyond the scope of what was initially noted in the storyboard; support as people, including the role of workers, family members, and guardians. Whereas support as systems focused on policies, education, and legislation. Questions were then raised of how best to strengthen the message about the critical role of supports in sexual health:

Kathy: ‘What advice do we have for support workers?’ is something that we’ve touched on in almost every interview. Do you still want to keep it separate per clip, or do you want to end with ‘what are the supports?’ or ‘what type of supports should support workers do?’ and then we kind of have everybody answer them?
 Joan: I might be easier to compare different people’s ideas if we heard them all together. Sometimes I forget what people said. Does anyone else feel that way?
 Aaron: Yea.
 Dennis: For sure!
 Mary: I’ve already forgot it.

Participants also went back and forth interrogating the ideas, raising questions, and developing skills regarding how the order of the clips can be put together to strengthen their message through video.

The editing phase became a layer of analysis in understanding the issues, barriers, and supports needed for persons with developmental disabilities in the area of sexual health. Collaboratively viewing the video clips also created a rich and powerful forum to investigate the topic as a group, where the process afforded the opportunity to respond to video clips, pose further questions around the various topics, and share lived experiences around the issues being explored. For instance, discussions centered on the topic of eugenics, human agency in the areas of love and relationships, and the systemic forms of discrimination in policy and support services.

Topics identified in video clips were also explored in more depth. For instance, in one video interview a participant shared that her dogs are integral in developing connections with people. However, through the editing process, an emergent theme was identified that connections with people provide a sense of belonging. The following excerpt is the initial interview on camera, followed by the conversation that occurred during the editing process:

- Thomas: How has your experience with dogs affected your life and your being in the Right to Love group?
- Mary [with her dog]: It's made me braver. I know with Lacey [name of dog] to help her overcome her fears, I've had to ask people, 'can I bring her into different places?' where I normally wouldn't be able to talk to those people. And I had to be able to learn to accept the word 'no.' And just kind of roll with the punches. Before I use to be scared just talking with people. And that's kind of helped me, helped open up a little more doors.

After viewing the film, Thomas and Mary continued their conversation:

- Thomas: As an interviewer I felt like I wanted to explore with you a bit more about how having your dogs affected you being in the Right to Love group.
- Mary: I think it affected me a lot. My dogs are an important part of my life because they give me the courage to connect with people. Lacey [my dog] especially helps me connect with people. Before I felt a missing connection in my life, which is why I wanted a dog. They've made me braver. And they helped open more doors for me through meeting people. I asked someone at [name of organization] if I could bring Lacey, remember? And that's how I got introduced to people, which brought me here to the Right to Love group. That wouldn't have happened if it wasn't for Lacey. In a way, my dogs help me connect with people, and connecting with people makes me feel like I belong.

The act of viewing video footage afforded participants opportunities to investigate their own reality, which concomitantly provided greater clarity to a person's situation. For example, over the course of study, participants explored how language impacts their identity construction, specifically when participants choose to include or exclude themselves as members of the disability community. In one video, a participant used the term 'they' in his interview to describe persons with developmental disabilities. After viewing the film during editing, another participant questioned why he referenced disabled persons as 'they' not 'we':

- Joan: I have an observation.
- Heath: Okay.
- Joan: You used the word 'they' instead of 'we' a lot. So you say they, people with disabilities 'they' have the right to have, to love. Instead of saying people with disabilities, 'we' have the right to love. I find when I hear 'they' I disconnect.
- Heath: Yeah.
- Joan: When I hear you say 'we' I get sucked back in.
- Heath: Yeah.

- Joan: Well I don't know, I'm not asking you to change it. I'm just [making an] observation. How do the others in the group feel?
 Dennis: Well, well, it's sort of inclusive when he says 'we.'

Through further discussions, Heath explained that he used this type of language because he was answering the question as a support worker, which is his employment background. Together, we discussed how Heath could best represent himself and his social location in a way he was most comfortable.

- Heath: I didn't realize I was using 'they' that much ... I am good at wearing different hats
 Thomas: But lets make sure people know you have these different hats

Heath decided to record a voice-over to clearly explain his language use and positionality of 'wearing different hats,' as a self-advocate, a support worker, and a member of the disability community. Prior to his video, he recorded the following voice-over: 'I've worked as a support worker, and I'm part of the disability community. So I'm addressing the right to love from several unique perspectives' (personal video).

Credibility and trustworthiness: quality criteria

At the end of the participatory video process, participants developed 14 videos ranging from approximately three to five minutes in length. The videos are also multi-modal representations of the core themes that emerged through the critical framing process. However, the use of participatory analysis does not eliminate the need for rigorous inquiry; weak interpretations can be overcome through ensuring that frameworks are grounded in quality criteria. Critical framing draws on the works of Herr and Anderson (2005) as well as Lather (1986) for quality criteria: triangulation, face validity, catalytic validity, and democratic validity. To uncover deeper insights into the topic of sexual health and disablement, triangulation of different data sources and methods was applied. Multiple data included arts-based collages, storyboard visuals, and raw video footage. These data were explored to consider different perspectives of the topic. For instance, participants viewed video interviews that captured perspectives of fellow participants as well as community members, and subsequently discussed these videos in relation to the topic and personal experiences. In this editing process, participants triangulated their lived experiences with those views expressed by people interviewed for the film.

Face validity involves recycling data analysis back to the participants (Lather 1986). For participatory video, we see how face validity occurs throughout the critical framing process: generative themes are identified through arts-based engagement. Subsequently, participants reflect on these themes throughout the storyboard process and in deciding on interview questions. Similarly, the collaborative editing process also involves participants interpreting, reworking, and delving deeper into the generative themes identified during the initial stages of the research.

Catalytic validity considers how people are transformed by being involved in the research (Herr and Anderson 2005). Across all three phases, participants located their own experiences within the larger social context. Through reflecting on the political and personal dynamics of sexual health and disability and creating a series

of videos visually representing their perspectives on the topic, the participants also asserted their own understanding of their sexual rights.

Democratic validity considers the degree of collaboration in the research process (Herr and Anderson 2005). Various modes of participation were reflected through pre-production, production, post-production to distribution. Participants also engaged in different roles and decision-making throughout the three phases of critical framing.

Discussion

This research is relevant to disability research because it considers how participatory analysis takes shape and unfolds in various spaces in participatory video research. Through critical framing, participatory analysis is exemplified through interconnecting arts-based methods, the storyboard process, and collaborative editing. Through these phases, participants identify and analyze generative themes through creative and dialogical forms of engagement, where the final videos are representations of the core themes that have emerged from the process.

In this study, participants also echoed that there are very few accessible places to learn or speak about sexual health. They also stated that in the context of the filming process, co-creating safe spaces was paramount to sharing personal experiences both on and off the camera. One participant remarked that the participatory analysis process 'provided a safe space to be myself,' and felt comfortable 'expressing opinions, asking questions, and disagree with each other.' Another person emphasized that feeling accepted by her peers contributed to feeling safe to share her stories; 'this is a safe group where people can say whatever they want. It's good to be able to do that. Lots of times I can't do that with my family.'

Several people indicated there was power in hearing each other's stories. For instance, watching one of the participants share his stories on film evoked a physical reaction for one individual: 'It's so powerful. I always cry when I hear it and when I see it. You know [turns to the participant], you don't say much and when you do say something so eloquent, I just get really excited.'

Exploring the process of participatory video analysis in the context of collaborative research also follows Sample's position that the participatory framework with persons with developmental and intellectual disabilities 'is not only reasonable, but moral, ethical, and necessary' (1996, 331). Participation is possible in different degrees for different people, and this should be respected in the process of engaging in research with people with disabilities (Sample 1996). Similarly, Chappell, Goodley, and Lawthom also state that inclusive approaches 'can be an important way of enabling greater involvement for people with learning disabilities in the research process' (2001, 47).

There were limitations to this study. Several challenges arose in the context of accessible participation within the editing stage, such as balancing choice, time, and reaching consensus around content. Certain participants who were more vocal and articulate also initially dominated editing decisions. All of these issues echoed the challenges of honoring the individual voice during participatory analysis and unintentionally privileging certain voices over others.

To address these issues, different techniques were explored such as asking each member of the group what they wanted to keep in and what they wanted to remove from the films. Final decisions were also made through reviewing video clips, revisiting the initial storyboard, and ongoing group discussions about sequences.

However, navigating these challenges of participatory analysis requires further exploration and discussion amongst practitioners, researchers, and community members to understand the various practices that can assist in collaborative editing while balancing a participatory and accessible approach.

This article provides a description of participatory video analysis. Findings suggest that through the participatory video process, participants interrogated social contexts in relation to their lived experiences. The critical framing process also opened up pedagogical spaces of learning with each other through sharing stories and celebrating human agency in research. By building on the current body of scholarship of participatory video, this research study offers insights into the process while contributing to the development of a deeper understanding of the potential for participatory analysis in the context of collaborative disability research.

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1. For further details on the overall research study as it relates to the dimensions of sexual health and the role of self-advocacy, see Sitter (2012).

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