

# Uplifting Voices and Images of Research Participants: Issues in Video Dissemination

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**Abstract** Video technology is increasingly popular for disseminating research results because its multi-sensory avenues for communication provide richer information than is often available in printed reports. Despite this advantage, issues inherent in video-based dissemination research have not been well articulated in nursing literature. In this article, issues of power, representation, participant autonomy, confidentiality, informed consent, intellectual property, and commercial use and profits are described and critically analyzed. The discussion is contextualized with examples from two original qualitative research projects involving women recovering from eating disorders and adolescents living with diabetes. Recommendations for future video research include giving as much control as possible to participants through negotiation of consent, confidentiality, and copyright ownership issues on an on-going case by case basis.

**Keywords** Video, Dissemination, Eating Disorders, Diabetes

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## 1. Introduction

Video data are one of the most multidimensional modalities of data available to qualitative researchers and are a unique tool to comprehend and re-present or represent participants' realities and contexts. Video provides a multi-sensory record that details gaze, expression, body posture, sequence, and gesture which can create dynamic learning artefacts [1] and give new kinds of access to speech and voice [2]. Using video data in collecting and presenting findings helps ensure that the richness and immediacy of the participants' voices and stories are not diluted or that selected extracts are not taken out of context by readers. Through conveying explicit examples, video can help ease the passage of change for individuals considering adopting new

behaviours [3]. In addition to more directly and holistically representing participants' experiences, video may effectively reach audiences with low reading literacy skills. This permits individuals to watch with others or in privacy at their own pace by using rewind and pause options [2]. The correspondingly high accessibility and acceptability can make research easier to grasp and more useful to non-academic individuals including policy makers and those in similar contexts as the participants who can relate to the images portrayed. The video-taped experiences of participants can raise awareness in healthcare providers [4] and, to this extent, begin to impact clinical practice. The increasing facility of dissemination options, from online journals to researcher created websites, provides the capacity to include video data to replace or accompany text-based dissemination. However, with such opportunity come some significant constraints.

While there has been substantial dialogue of issues surrounding video-based data collection, there is a paucity of discussion about video-based *dissemination* in nursing research. To address this gap, two video projects that were completed independently – one of the recovery experiences of women with eating disorders who reside in a rural underserved Canadian province and the other of adolescents living with diabetes in a large advantaged Canadian city – were scrutinized with the aim of laying a foundation for further video research dissemination. These projects were chosen because of the researchers' access to them and experience as principle investigators. The first author has a program of research in eating disorders and a private practice providing long-term care and services to women seeking recovery from eating disorders. The second author has established her research laboratory in chronic illness inclusive of diabetes mellitus. Including two different participant samples enabled richer understanding of the issues inherent in video dissemination. Common issues related to power, representation, participant autonomy, confidentiality, intellectual property, financial conflict of interest, commercial use, and profit

were critically examined. Based on this critique, recommendations are put forward for on-going negotiation of participant consent, any use of identity blocking technology that preserves confidentiality and copyright ownership in future dissemination initiatives.

## 2. Two Qualitative Research Projects Using Video

In the two research projects that involved women recovering from eating disorders and adolescents living with diabetes mellitus, video technology served as the primary strategy to enter participants' worlds and share the findings. Keeping in mind that audio-visual materials enhance learning and retention through their visual vividness and power of impression [5], video helps represent and communicate complex lived realities to make the research findings more acceptable to knowledge users who prefer to view "real" people living in "real" situations.

### 2.1. Women's Recovery from Eating Disorders

During a feminist grounded theory study of women's experiences of recovery from anorexia nervosa [6], the first author was approached by a local film producer and asked to make a video based on this research. Delighted with the prospect of raising public awareness and helping others struggling with eating disorders, the original research participants helped to recruit other women as video participants. One mentioned "I know a woman who is writing a book about her experience with anorexia. Can I ask her if she wants to be in the video?" Women were also attracted to an information session about the proposed video project via posters placed in local hospitals, clinics, and community bulletin boards. The researcher and film producer addressed questions about the project in as much depth as possible and encouraged potential participants to consider taking part in the research. Communications between researcher, film producer, and potential participants were relaxed as there was no power differential between them. The expertise of the participants in having managed their recovery processes and the knowledge and skills of the researcher and producer were delimited. The original plan was for the video participants to represent the findings by reading extracts from the interviews conducted with the original research participants. However, the researcher questioned if using the knowledge derived from the original study might limit or suppress the contributions of the new participants and, in this way, compromise the validity of the study. Conducting interviews with new participants would create an opportunity for the researcher to test the validity of the theoretical model developed in the original research. Accordingly, the new participants were invited

to share their own stories in videotaped focus group and individual interviews. The three participants were Caucasian and ranged in age from 19 to 49 years. They recounted experiencing multiple negative events like abuse, clinical depression, loss of family members through death or illness, role overload, and overarching need to gain some measure of control in their lives. Two had received treatment locally in paediatric and psychiatric units of general hospitals; one had left the province for an extended period to attend a specialized treatment centre in another province. Treatment was perceived by the women as being subjected to further loss of control. Following each interview, individual participants met with the researcher and film producer to review the video-taped story and choose the clips that best represented the participant's recovery story. Expressing curiosity about and desire to get to know each other, the participants all requested and consented to meet as a group with the researcher and film producer. Collaboratively analyzing their video-recorded stories with the researcher and film producers, the participants became the core production group in deciding how to portray their experiences. The process was formalized as a separate participatory action research project with the resulting research product, the *Through True Eyes* video [7], developed as a resource for women, families, and healthcare providers.

### 2.2. Adolescents Living with Diabetes

This video ethnography [8] explored living with diabetes from the perspective of adolescents, their parents, and their health care providers. Drawing from Rich [9], video was used in conjunction with experiential interview and observational data to illuminate how adolescents perceived and experienced their daily choices about which aspects of diabetes they would attend to. Eleven of the 22 adolescents who participated in the interview/observation part of the study choose to take digital video camcorders. Two other participants also took a camera but did not return any video data, explaining that they were too busy or felt too self-conscious to tape themselves. The researcher asked each participant to record in any way, what their lives were like on a daily basis. This gave the adolescents maximal control and creativity over how they could express themselves and who they would include in communicating their perceptions to others. Participants filmed clips with family and friends at home, school, and diabetes summer camp. Some used the cameras to record personal diaries or to offer personal accounts. These raw videos formed the basis of subsequent interviews and were edited together by the adolescent participants and researcher to represent dominant themes in their experiences. Videos were also made of these adolescents' visits to the diabetes education clinic and the interactions between health professionals, parents, and the adolescents.

The research focus was primarily on using the video data to understand how adolescents balanced the demands of diabetes within the context of their daily life routines, relationships and goals.

### 3. Issues

In conducting the research projects with women recovering from eating disorders and adolescents living with diabetes, issues of an ethical nature were confronted that complicated using video medium. These issues which involved representation, participant autonomy, confidentiality, informed consent, intellectual property, and commercial profit exceeded the guidelines provided in current professional codes for conducting research with human subjects. Transcending the issues required critical reflexivity and perspective taking on the part of the researchers.

#### 3.1. Issues in Representing Participants

Working with participants to create data and verify acceptability of the clips for the final video products, the researchers in both projects strove to convey both the common themes and unique individual situations of the participants as well as to engage and maintain audience interest. From this need to balance science with its art arose issues of representation. These issues concerned equality of airtime, co-opting of voices and images, and reactivity.

##### 3.1.1. Equality of Airtime

The eating disorder project participants specifically wanted their individual recovery scripts incorporated into the final product, the *Through True Eyes* video [7]. Having gone through the “hell of this illness” and the “trauma of treatment,” they wanted their experiences and struggles to count for something by being included and shared with others. One participant expressed “I want to get my story out so others can perhaps not succumb to eating disorders like I did.” While keeping in mind that there is always choice about which threads or themes in the data are illuminated and explored and which are not, it still was not possible to give all participants equal airtime in transforming over eight hours of video recording into the final 23-minute video product. Only essential clips could be used to represent the phenomenon of recovery, and the participants varied in their ability as storytellers. Therefore, an individual participant’s desire for a greater profile may not have been accommodated because of the risk of distorting the main messages of recovery.

In the phase of videotaping clinical consultations of adolescents living with diabetes, the researcher spent several months in non-participant observation at the clinic, following adolescents through their visits or shadowing

the nurses, dieticians, physicians, counsellors and social workers. The nursing staff agreed to participate in being videoed with adolescents, despite some initial trepidation that their “mistakes” would be obvious. Of the clinic’s three nurses, two were experts in diabetes self-management support and one was within her first 6 months of practice in the clinic. In contrast, other health professionals in the clinic declined to be videotaped, explaining that their previous experiences of being taped in their professional education were not constructive and they chose not to do this although they permitted observation, and informal interviewing about their work and interactions. Thus, while the intent of the study was to explore the interdisciplinary teamwork within the diabetes clinic, the video consultation phase specifically focused on the nursing interactions.

##### 3.1.2. Co-opting Voice and Image

In the *Through True Eyes* video, the researcher was edited out of the final product with her role conveyed in a brief story line in the credits. This co-opting, described by Clandinin and Connelly [10] as the overriding of researcher voice and image, was deliberated at the outset of the editing process, as the intent was to re-present the participants’ stories. Unlike other research, such as an inquiry into pressure ulcer prevention and treatment that did not reflect the priorities of those who took part [11] and a truly participatory project that enabled everyone’s voice to be heard [12], the *Through True Eyes* project focussed on having the voices of the participants heard and understood – to the exclusion of the researcher’s voice. While not included for this project, a “behind the scenes” commentary or written accompaniment would have been valuable to detail the key role of the researcher in shaping the process and outcomes of the project.

Co-opting voice and image manifested in different ways in the diabetes project when the participants themselves created data. The majority of the participants, despite being asked not to edit their own tapes, did edit prior to returning them to the researcher. In the few instances where there was no editing, the participants were vocal about clips they would rather delete. Clearly participants felt some aspects were best not publicly available and this was possible as consent for the video part of the study separated the participants’ participation in the video for the purposes of understanding from permission to use video clips for dissemination purposes. Discussing with participants the content they had or would like to have deleted facilitated understanding of hidden dimensions of living with diabetes.

##### 3.1.3. Reactivity

Behaviour change in response to awareness of the camera, termed reactivity, could adversely affect the “naturalness” of the recording [13], trigger negative emotions of worry and nervousness [14], and thus

influence the representation of the phenomenon. There is controversy in the literature regarding the extent and duration of participant reactivity. Strand, Gulbrandsen, Slettebø and Nåden [15] found the anxiety and insecurity some participants attributed to video recording in the beginning of the study improved after the first taped session. In contrast, Semeniuk and Riesch [16] found that 20% of their sample or one out of five dyads reported that it did not feel natural for them to talk in front of the camera, and they did not progress to feeling more natural even by the sixth taping. Anticipating added reactivity related to having the *Through True Eyes* video professionally produced, the researcher spent time interacting with each woman prior to taping, discussing the study purpose, and reassuring that there were no “right answers” and that the participant would be free to have any aspect of or the entire interview deleted. The presence of the film production crew actually contributed to participants’ comfort by enabling the researcher to attend fully to participants without the worry of attending to the camera. Nevertheless, one *Through True Eyes* participant wrote out and rehearsed in advance what she wanted to communicate, resulting in a mechanical, less interesting account of her recovery. A more genuine recording was eventually achieved when the researcher left the room for the participant to tell her story directly to the camera. While the participant later described that the task of actively striving “to not pay attention to the camera” was easier without the presence of others in the room, she acknowledged that she continued to notice the camera which “made [her] more conscious” of being videotaped.

In the Diabetes project, participant self-presentation was also complex. Half the adolescents who participated in the clinic observations and interview declined to use the camera, citing time pressures or embarrassment with the idea of taping and viewing themselves on camera. Some of the clips from those who did use the cameras displayed stilted, insincere sequences and messages. Although the adolescent participants appreciated having unlimited video footage to tell their stories, some were uncomfortable conveying themselves as “experts.” One 13-year-old participant made a video that appeared to contradict her personal experiences. She described her video as a “guide to living well with diabetes.” The first scene showed her sitting on the floor of her bedroom, leaning against her bed, with pictures of characters from Winnie the Pooh on the wall behind her. It was her intent to make an “inspirational” video to reassure other adolescents that “surviving with diabetes” was possible, even though this was not true for her. She spoke using written notes held off camera, and her tone and non-verbal language accumulatively did not sound “real” when the researcher first viewed it. However, in constructivist inductive inquiry [17], the question was not whether the content reflected a common truth, but to wonder what was happening, and why. This approach was an aspect of the

research designed to understand the participant’s account of what she was trying to relay in her video rather than assume that the video clip reflected “untrue” data that were inconsistent with other sources of information about that adolescents’ life with diabetes. Having the researcher and participant view these data together provided the participant opportunity to give voice to the unexplained aspects of her experience that she had not shared with the diabetes clinic or in her prior interviews. The video proved essential in exploring issues of self-identity and public and private face and her need to be seen as a “normal teenager” despite feeling unable to fit in with the “normal social world” because of her diabetes. As Flicker [18] advises, a video story reveals important parts of a participant’s world and is an equally valid narrative despite any apparent incongruence in terms of the “absolute truth” of words. Another participant recorded a diabetes camp activity that was valuable, as the responses and reactions of the entire group of adolescents revealed their feelings of dys-synchronism from the non-diabetic world and their attitudes and beliefs around stigma and ostracism from peers, family, and the public.

### 3.2. Participant Autonomy

In both projects, respecting participant autonomy potentially jeopardized the research products by the withdrawal of video data. This conveys the need to continue to safeguard participant autonomy from the start of a project through to the dissemination of its findings. Giving the participants of the diabetes project the freedom to record what was important to them without restrictions or directives apart from recording verbal consent from others they filmed did not prevent discomfort discussing the clips they produced and selecting clips not to be included in dissemination activities. In the *Through True Eyes* project, participants were offered multiple opportunities to modify content and language, and maximal control over having their images and interviews removed from the video altogether. Some participants, dissatisfied with their clips, requested aspects of their interviews to be re-taped. Such high level of participant autonomy was possible because the film company rather than an external funding source fronted the production costs of the *True Eyes* filming and the researcher and the film producer agreed.

### 3.3. Confidentiality

In non-video dissemination, the researcher has the option of creating a story line with multiple anonymized quotes; but in video, the quotes are indisputably linked to the participant. Due to its intersecting audio and visual layers, video “show[s]” and not just “tell[s]” a person, situation, or phenomenon [19]. The major risk from presenting images and voices is social harm in the form of

public identification, criticism, embarrassment, or isolation [19]. In the *True Eyes* project, the social risk was heightened by living in a small community and by not camouflaging identities through such techniques as facial blurring or mosaicking and voice modification which would have lessened credibility of participants who wanted to be directly seen and understood as people who had struggled with eating disorders and recovery. Although unusual for a person experiencing what is considered a mental illness to show such courage and be willing to come forward, one participant explained:

What message would I be putting out about recovery if I did not show my face and let others hear my voice and know my name? It would look like I was still trying to hide behind the eating disorder. No, I am not proud of having developed it [the eating disorder] in the first place, but, yes, I am proud that I recovered from something that kills so many. It was hard work to get over the eating disorder because it was not about food and not eating. And when you struggle once you've had an eating disorder, everyone automatically assumes it's the eating disorder you are struggling with. They start asking about your weight and they watch you closely while pretending not to. They don't seem to understand that sometimes other mental health symptoms are just as debilitating. So, that is why I hope my story can help others understand the bigger picture.

The researcher was pulled between her institution's ethics review board requirements to preserve confidentiality, and the request of the research participants to appear on camera to show their realities and share their experiences. Ultimately, the participants submitted signed affidavits of their wish to not have their names, voices, and images modified in the *True Eyes* video. This was also true in the adolescent project where parents and adolescents signed consents acknowledging that images and voices would not be disguised if used in public. On one hand, those adolescents who chose to participate wanted their stories to help other adolescents; but on the other hand, they did not want the clinic staff to see that they had at times used sarcasm in their portrayal of treatment decisions. The videos were judiciously used in local presentations after an audience member, of a similar age to some of the participants wondered if she recognised the participant as going to the same high school.

### 3.4. Informed Consent

The recovering participants all gave permission to the researcher for their interviews to be used to create the *True Eyes* video. In addition, they signed a release form granting the production company permission to use their interviews. Similarly, in the diabetes project, separate written consent was obtained for the individual interview,

the clinical observations. And the video diary phases of the study. Participants and their parents, if under 18 chose whether they provided written consent to use of the video data solely for data analysis or if selected video clips shared with the participant could be used in public. It was crucially important to renegotiate consent at every instance of videotaping and to explicitly ask about any observed indicators of uncertainty or embarrassment at the time, or when the participants' own videos were shared and discussed. Ultimately, very few video clips were reserved for analysis only, with participants indicating that if their video would be useful to help ease the journey of another adolescent living with diabetes, it was sufficient for their consent. On-going consent was especially needed in the recovery project because participants could not realize the full impact of hearing and seeing themselves until the *True Eyes* video was prepared and ready to launch. They were free to withdraw their consent after viewing the in-progress and completed video, and this degree of autonomy was reflected in the informed consent process followed in the conduct of the research.

Although the adolescent participants living with diabetes were given copies of their videos for personal use, the researcher was required by the ethics review board to tell these participants to not distribute the videos on the Internet. It became apparent that there were two overlapping issues within these requirements for consent. First, it was neither realistic nor ethical to attempt to limit what participants did with their data. Second, it was questionable if consent could hold meaning when there was a lack of control over who would see the images. The ease of transfer of video data [20] and the current state of internet security [21] enable mass distribution of images and voices with no protection by the guidelines and laws within which the data were created. Within this cyber milieu, researchers may not be able to limit access to the video footage [22, 23]. Depending on the amount of attention paid to adolescents living with diabetes or the eating disorder recovery stories, this could result in downloaded images appearing on coffee mugs and Tee shirts, something well beyond the intent of the projects and researchers' control. The ethics review board's intent was to prevent this through researcher actions of uploading video data; however, no control over participant actions beyond a request not to do this was possible.

### 3.5. Intellectual Property and Commercial Profit

The term *intellectual asset* is a legal reference describing an investment in brands, technology, or creative works; it includes intangible assets such as human knowledge and novel designs [24]. Intellectual assets have value in today's knowledge-based marketplace and are considered ownable property when transformed into tangible forms. Because of their huge personal investment and commitment to the video disseminations, the participants of the recovery and

diabetes projects felt greater ownership of process and product than they would have if they had merely left interview forms and stories with researchers. Diver and Higgins [25] contend that researchers are only co-creators of knowledge when the research is derived from fieldwork with local stakeholders who are experts in their lived experiences. Although legally, the researcher with the support of an agency or institution has created the data and thus to some extent has ownership; ethically, the sustained, intensive contribution of the participants implies ownership.

In the context of video as products of research, the disconnection between the legal definition and the ethical mode of practice revolves around commercial profit. Whoever owns the research receives the financial benefits of its video dissemination. In the *True Eyes* video, the participants' names appear on the screen, but they do not receive royalties. The film company recouped production costs and additional revenue generated from the sales of the video was donated to a provincial not-for-profit eating disorder charity. This option to distribute profits, chosen by the researcher with input from the participants and film producer, was deemed the best amid competing claims of the film company, researcher, and participants for the intellectual property, the *Through True Eyes* video.

## 4. Discussion

The issue of social power underlies and interplays with the issues of representation, participant autonomy, confidentiality, informed consent, intellectual property, and commercial profit. Social power is the degree of influence that individuals or organizations have within their society [26]. According to Feldman [27], types of social power may include the authority granted to a person stemming from a position in a group or organization, coercion, expertise, information, ability to reward, and identification with a referent leader. The power of authority, coercion, and ability to reward may manifest as power-over others; power as expertise, information sharing, role modeling and may provide power-to and power-with others. The influences of power on rigour/relevance, scholarly evaluation of video dissemination, and commercial profit are discussed for the recovery and diabetes projects.

### 4.1. Power

The usual danger is that those in positions of power (e.g., researchers, healthcare providers) co-opt the voices of those who are vulnerable (e.g., research participants, patients) and thus exert a power-over differential. In the recovery and diabetes projects, however, the researchers' efforts to uplift participants' voices and images through providing them greater autonomy such as involvement

throughout the editing process and control over the final presentation seem to have fostered the power-to/power-with differential. For instance, the adolescents in the diabetes project controlled the raw data, filtering what the researcher could directly access, analyse, or utilize for dissemination. The participants of *True Eyes* became the content experts of the video. The researchers' clinical and research experiences with the target populations of women and adolescents enabled them to maintain a position of mutual respect and engagement which fostered perspective sharing on the part of the participants. "True participation is based on a message of dignity and acknowledgment of one's equal right to contribute knowledge and an experience that matches the message" (p. 286) [28]. This egalitarian position, the hallmark of efficacious communication with vulnerable populations, is often difficult to enact in clinical institutions where the focus is at times on tasks and routines [29]. Yet, as principle investigators responsible for the conduct of the projects, the researchers noted that allocating power to the participants did not lead to conflict between researchers and participants because of the high level of respect and collaboration between participants and researchers and the researchers' beliefs that the participants were qualified to make these decisions. In fact, creating the power-to/power-with differential cast the researcher into the role of exploring with participants their assumptions underpinning editing decisions, and this, in turn, facilitated exploration and greater understanding of issues of reactivity and confidentiality otherwise not explicated. Co-opting of researcher voice moreover allowed researchers to join participants as fellow problem solvers with the shared intent to create a helpful product.

### 4.2. Rigour-relevance Debate

A critical component of video dissemination is its appeal to an audience. Yet, the academic world is largely of, for, and by academic scholars [30]. Researchers may tend to focus on rigorous analysis of and inter-relationships among concepts to explain a phenomenon, rather than on how the insights culled out of the research can help solve real world practice problems, because it is difficult to be both scientifically rigorous and practically relevant [31], communication elements of rigour cannot be seamlessly integrated into relevance. To illustrate, a focus on rigor may point toward establishing rigid laws that are at too high a level of abstraction to be applied to specific situations or are too narrow for direct application in practice. The inaccessibility of such research and the use of academic jargon create barriers to relevance. The high level of participant autonomy and shared involvement between researchers and participants in aspects of video-based data collection, analysis, and editing of final products helped to keep the focus on real world problems associated with eating disorders and

diabetes, thus helping to build the capacity of participants to be involved in research design and dissemination which may allow findings to be more useable to them. The potential of the video dissemination to convey a different purpose than the research originally intended was prevented through using scientifically rigorous methods accepted by peers and the ethics review boards, ongoing researcher reflexivity to maintain awareness and balance between being scientifically rigorous while relevant to practice needs, and submitting the research products to peer review and external critique. These efforts helped redress what Panda and Gupta [30] label as the “rigour-relevance gap” (p. 157).

### 4.3. Devaluation of Video Research

The effort of appealing to an audience may be seen as merely entertainment and therefore as less prestigious than traditional dissemination through high impact journal publications. Such academic devaluing of video dissemination is not a new problem and is similar to the problem of researchers who publish in consumer-oriented venues less esteemed than academic forums. These researchers who choose non-traditional means for dissemination are disadvantaged in academia and their work may be seen as stalling disciplinary knowledge development. For instance, Annells [32] pointed out that video dissemination may render research results ineligible for meta-synthesis. The usual practice in research syntheses is to “limit the literature search to only research published in peer-reviewed journals” (p. 135) [33]. Indeed, in preparing this paper, no meta-syntheses that included video disseminated research findings were found.

Given devaluing of video dissemination, its status as stand-alone research warrants discussion. The *True Eyes* project was initially regarded as an extension or application of original research conducted to generate knowledge of how women recover from anorexia nervosa that would help make a difference to the lives of women and guide practice. *True Eyes* became a new research project in its own right through including new participants, an emancipatory design, and a professional film company. Because the project had changed in these ways, the researcher returned to the ethics review board to get approval for ensuring the scientific integrity of the project. The lesson learned is that issues such as the likelihood of making a movie cannot always be anticipated and negotiated as the nature and the impact of the findings may not be imaginable at the start of a project. Such issues need to be detected and discussed as they surface.

### 4.4. Commercial Profit

Concerns about the ownership of the research components of video data and the research products of the dissemination video and presentations were not

completely resolved. Various stakeholders continue to have claim including the researchers who conceptualized, designed, and implemented the studies; the academic institutions holding the copyright for graduate and postgraduate these projects; publication agencies holding copyrights to subsequent publications; the *True Eyes* film company’s investment in and control of the dissemination product until sales covered production costs; the national external granting agency requiring acknowledgement of the diabetes project; and the participants themselves. It is possible that the claim of the participants, never overtly expressed, has been possibly exploited by the more powerful stakeholders in the projects.

### 4.5. Contribution of Video Dissemination

From a critical perspective, the video dissemination projects provided advantages that balanced its potential risks. Our participants used video technology as a way to speak for themselves and their communities. Their participation in the research and having control over the content that would be released assisted them to fashion their identities for the audience, contributing to their sense of pride, accomplishment, and empowerment. In addition, the knowledge that the *True Eyes* participants would be readily identifiable within the research may have created higher levels of accountability, as the researcher and film producer had to personally address participants’ reactions and concerns upon seeing their portrayals in the research findings. While guidelines caution researchers to avoid using non-confidential data and methods, the use of video design and technology that did not block participant identity served to achieve a number of psychological, political, and educational benefits of self-representation.

## 5. Insights and Recommendations

When the video research projects were conducted, the existing ethical guidelines for video-based research were inadequate. The recovery from eating disorders and living with diabetes projects were successful because the participants wanted them and were committed to seeing them through. The success of the projects may be also attributed to the researchers’ commitment to exploring the influence of power on participant self-representation, striving to share power with participants, and making decisions visible and discussable. From these video research experiences, strategies to reduce power differentials in research relationships are recommended.

As a starting place for identifying researcher responsibility within the implementation of video research, the first concern is to ensure participants are as fully informed as possible. This involves informing them not only about standard research expectations such as research procedures, time involved, any inconveniences, benefits,

and risks but also about likelihoods unique to video-based data such as loss of control over video images and products once published or released in cyberspace and potential for participants to be recognised. Although it is imperative that participants who choose non-confidentiality understand this potential from the onset of the project, Anderson and Munzo-Proto [19] ask, “How can we best ensure that participants are informed of potential risk?” (p. 385). The answer is to offer participants information about this type of risk along with any technological developments to help bolster cyber security of images.

In negotiating on-going continuing consent, researchers could consider if the needs, rights, and goals of the participants would be better served by creative commons licensing or other legal frameworks. Also, researchers could include established protection measures such as explicit and mutual copyright ownership agreement in providing information to potential research participants. This action would raise awareness of the risks and added measures for protection as well as help foster power sharing between researcher, participants, and other relevant stakeholders. It would be helpful for all stakeholders to address ownership issues at the start of video production and on-going as needed.

Given the trend toward expecting researchers to engage in knowledge translation (KT) of their findings to end users of the research and toward supporting KT as concurrent or corollary research by national funding agencies, video dissemination is a valuable tool to include in research protocols. While the recovery and diabetes researchers chose to use real people, white boarding approaches or sketches of participants may also be considered. If not initially foreseen in the original proposal, KT could be prepared as a separate project and presented for ethical approval to ensure its integrity.

The care taken by researchers to develop and nurture relationships of trust, openness, and mutual accountability with participants is the key to successful video use in research and dissemination activities. Collegial relationships are essential between researchers, participants, and other stakeholders including the film producers, and so as much control as possible is given to participants. Prioritizing participant-as-stakeholder engagement enhances the quality and relevance of evidence in qualitative health research by addressing the basics, answering genuine questions, and making a difference [34] which facilitates giving them a more authoritative voice than occurs in conventional research methods [36]. In *True Eyes*, this took the form of enhancing their well-being by such measures as videotaping participants in natural settings where they felt comfortable, and willingness to remove frames or clips such as an unflattering smile or mispronunciation to ensure data best represented their experiences. The experiences with participants who expected and responded

to the researcher’s involvement throughout the recovery and diabetes projects preclude adopting a non-participatory, detached approach. Other nurse researchers [34,37] have asserted that a non-participatory stance is impossible as participants are naturally inquisitive and enthusiastic and their questions and social talk cannot be ignored without alienating them.

Endorsing participants as content experts enhances validity and participant autonomy. Similar to Vandermause et al.’s, [34] and Whiting, Symon, Roby, and Chamakiotis’ [35] findings, reflective analysis of the recovery and diabetes video recordings brought to light the extent of participant expertise in making sense of their environments and situations. While their experiences are crucial to understanding eating disorder recovery and adolescent diabetes, the non-confidential nature of video need to be comprehensively explored with participants. This could include negotiating between researchers and participants the use of identity blocking technology on a case-by-case basis as well as honouring their choices that publicly reveal their identities. In a situation wherein consent is not obtained, there is no choice but to mask identities or to avoid its use for dissemination. Seeking out the participants’ perspectives of the importance of confidentiality is mandatory to ethical video research.

Given the widespread infiltration of video-based social media in contemporary society, researchers require specific training for video-based approaches. If video as product is the intent, training in editing and presentation is important as editing even parts of seconds off a video clip can change the meaning and intent. The expense of video recording as a method of data collection justifies technical competence on the part of researchers [36]. In addition to training, inclusion of professional film editors enhances quality of data and participant-researcher relationships, as the researcher is freer to respond to participants without worrying about the technology.

In keeping with other researchers’ suggestions to position video methods within a reflexive methodology [19,34,37], researchers need to be reflexive, critically appraise their work, and open it to others – in particular, their research participants. The presence of the *True Eyes* researcher was made invisible in the finished video -- i.e., her role in interviewing and prompting participant reflections was edited out of the final product. In both projects, researcher presence varied throughout different presentations of the findings. To illustrate, the focus in the *True Eyes* product was primarily on participants’ insights while the researcher role was de-emphasized; yet in other presentations of the *True Eyes* project, the researcher’s role was emphasized.

Presenting findings from the diabetes project to professional audiences risked taking short clips out of context or having particular exemplar interaction strategies perceived as representing the entirety of the clinic interaction. In this context, the researcher provided

background about the entire context and discussed the validity of interpretations of specific clips within the entirety of the interaction beyond the clip shown. For example, although used rarely, nurses could utilise closed answer questioning strategies. This was explained as a way to reduce ambiguity, reduce potential adolescent embarrassment by focusing on specific information, and occasionally actively probe for information when there is perceived reluctance by the adolescents to talk about their diabetes self-management practices. Often this strategy was successful in its intent but occasionally it would result in the adolescent shutting down. In one presentation however, when examples of each of these effects were presented, an audience member challenged the nurses' practice as unprofessional by assuming that this was the nurses' preferred and only communication strategy. Necessarily, the researcher provides context about the nature of the nurse-adolescent relationships as the interview data from staff and adolescents about the clinic experiences cannot be extracted in the interpretation of a single communicative act. This range of visibility and explication of researcher oversight/process is necessary because of the different audiences (e.g., clinical or lay) and the different aspects of the research projects to share. According to Collier and Wyer [38], multiplicity of positionings, as a collective, might come closer to honestly representing the research than any single account could.

Alongside of overtly conveying the researcher role, a crucial research process is to "reveal the constructedness" (p. 589) [36] of the products in written accounts of the video research. To help accomplish this, it is best practice for researchers to supplement video modes with traditional modes such as detailed field notes to collect information about unobservable processes of thoughts, attitudes, feelings, and perceptions and to check interpretations of perceived social presentations as well as validity of findings with participants. A reflexive methodological approach is recommended for this. Panda and Gupta [30] further propose employing twin faculty groups with one ensuring rigour and the other ensuring practical relevance. If such opportunities are not available, practitioners are encouraged to be involved at a later stage to vet the utility and applicability of the research findings. This helps ensure that research is informed by and integrated with practice and real-world experiences.

The final recommendation is that nurse researchers using video-based data publish their experiences and learning because current disciplinary scholarship on ethical considerations is limited. Vandermause et al. [34] argue that establishing researcher reflexivity, giving participants maximal control over issues of confidentiality and data ownership, and developing meaningful collaborative relationships with participants are foundational to the ethical conduct of video research and patient-centered qualitative research approaches. Skills in reflexivity and collaboration which are already integral to excellence in nursing practice with patients can be

transferred and further refined for research approaches with participants. As nurse researchers increasingly use video technology to produce data and disseminate research, communication of such learnings will help to strengthen the ethical underpinnings of video research methodology while it continues to develop.

## 6. Conclusions

The use of video in disseminating research presents unique challenges that have not been resolved. Expanding expectations of nurse researchers and interdisciplinary research teams will facilitate researchers' opportunities to work with professional, ethical, and other decision-making bodies to infuse principles of patient-led, rigorous video modalities within a range of qualitative methodologies. It remains crucial for researchers to continually reflect on their research practices to understanding how principles of ethical practice, reflexivity, scientific integrity, and moral responsibility to and with participants are manifested in their research strategies and goals. Through attention to power issues underlying and intersecting disciplinary knowledge development, research relationships are enhanced and stand a better chance of improving the health and well-being of those served through nursing practice. The need to make explicit how researchers act reflexively in the field, explaining how their deliberations and methodological decisions are central to the successful and ethical use of the video as research output, is stressed. There is further need for exploration, discussion, and agreement about the future impact and advances of video technology on research, the value of video dissemination to disciplinary knowledge development, the impact of video on the research process, and methods to analyze video recording.

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