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Healthcare providers' experiences as arts-based research participants: "I created my story about disability and difference, now what?"

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Abstract

Little is known about the experiences of healthcare providers as research participants in qualitative studies employing methods that encourage disclosure of their own disabilities. In this paper, we describe the experiences and implications of creating personal stories of disability and difference for healthcare provider participants in an arts-based study. The study design is a supplementary secondary analysis of a subset of data from a larger study focused on transforming negative concepts of disability and difference entitled, *Mobilizing New Meanings of Disability and Difference: Using Arts-Based Approaches to Advance Healthcare Inclusion for Women with Disabilities*. This supplementary study explores the experiences and perspectives of 17 healthcare provider participants who completed semi-structured interviews following creation of a multi-media story about their experience of disability or difference. Using creative non-fiction methods, two narrative streams are identified about healthcare provider experiences and the impacts of participating. The first addresses shared positive experiences about the research. The second entails more ambivalent reflections on their involvement as participants. The tension between the two experiences generates considerations to forward a mutually beneficial alliance to disrupt ableist understandings in healthcare and reveals new meanings of disability that are agential and integral to the stories and storytellers themselves.

Keywords:

disability and difference; multimedia storytelling; healthcare providers; creative non-fiction

There is an evolving body of literature regarding the implications of participating in health-related research studies for individuals from disenfranchised populations. The literature, however, has little to offer about experiences of people who participate in qualitative health studies that involve disclosure of sensitive and often stigmatized subject matter, such as living with a mental or physical disability. Even further, few (if any) studies ask healthcare providers to narrate their experiences of living with a disability or to describe the implications of participating in qualitative research specifically designed to document and share those experiences. The purpose of this paper is to capture and analyse the experiences and implications of healthcare provider participants creating first-person multimedia stories (short videos) about disability in an arts-based project that focused on transforming negative concepts of disability in healthcare. We ask: 1) What are healthcare providers' experiences of creating multimedia stories focused on professional and personal aspects of living with disability for a qualitative research study?; and 2) What do they perceive as the risks and benefits of such participation? Within this study, disability or mindbody difference includes, but is not limited to, visible and invisible physical, emotional, and mental difference.

Literature Review

Qualitative researchers have explored the individual experiences of research participation. Through juxtaposing the existing literature with her own experiential knowledge as a research participant, Dennis (2014) proposed that praxis, identity claiming, and distinguishing between facts and interpretations were central to having positive experiences in qualitative studies. Dennis described her own positive experience as a research participant as encompassing her inclusion, recognition of her contribution, acknowledgment that she was "good, okay, appropriate, acceptable, sensible person" (p. 404) by the researcher, and authentic representation in study

results. Earlier work by social work researcher-clinicians McCoyd and Shdimah (2007) identified that participants described positive experiences of participating in interviews framed by respect and relational regard, which for them entailed being understood and creating a shared voice with others through the merging of stories.

Newton (2016) emphasized the importance of considering researchers' and participants' divergent goals in research. Collecting meaningful data for generating knowledge is a common goal for researchers. Informed and consenting participants are made aware of the researcher's goals, and yet may be moved to join a study to fulfill their own needs such as personal catharsis, raising awareness, making sense of experience, and enacting change and/or social justice. Additional motivators for research participation reported in other studies include: learning about self, promoting healing, becoming knowledgeable about a topic of interest, connecting with community based on shared experience, helping others, and advocating for a cause (Bradbury-Jones, Steward, Irvine, Sambrook, 2011; Townsend & Cox, 2013; Wolgemuth et al., 2015). Cox and McDonald (2013) conclude that the common compliance-based ethics orientation to recruitment must be extended to include an interactive approach wherein researchers ask prospective participants what they expect from research and how they understand their responsibility as participants. This approach, they argued, would change "researcher-participant relations and participant protection practices and policies" (p. 230). Decker and colleagues (2011), however, note that it may not be feasible for all participant aims and needs to be met through research processes. This is particularly relevant when participants share emotionally-charged experiences, such as those of violence, grief, and suicide. Under such circumstances, they may underestimate the degree of distress that they will experience in talking about traumatic events to a researcher, thereby impacting their experience as a research participant.

Corlett (2012) proposed a framework of research interviews as a dialogic process of learning in which participants interact with researchers to story their experience, make meaning, create order, engage in critical self-reflexivity, become aware of and change language use, and recognize a difference between past and present tendencies. They described research participants as experiencing unpredictable physiological, emotional

or cognitive moments that "strike" them and trigger critical self-reflexivity and learning by questioning ways of understanding and being. From a relational social constructionist perspective, Corlett encouraged participants and researchers to be aware of "striking" moments that can elicit self-reflexivity and learning during research to optimize the benefits of participation. Within this and other qualitative studies designed to take participants through a process of critical self-reflection and offer feedback about their experiences, new states of being are possible within fluid and genuine researcher-participant relationships (Elliot & Bonsall, 2018; Newton, 2016; Probst, 2016).

In the existing literature focused on the implications of participating in research requiring disclosure of potentially stigmatizing information, Bibb and Skewes McFerran (2017) examined the experience of people whom they classified as living with "severe mental illness" in completing self-report outcomes measures following a music therapy intervention. Participants described the measures as difficult to understand and complete, which contradicted the original goal of the study, to empower those with a mental disability[1] and support their recovery. Moving beyond the question of whether individuals experience harms *or* benefits when participating in research on sensitive issues, Decker et al. (2011) found that women with histories of trauma experienced both distresses *and* benefits as research participants: they were more likely to experience "bother" when responding to questions about maltreatment and more likely than those without adverse histories to find participating in such a study beneficial. Wolgemuth et al.'s (2015) thematic analysis of interviews from multiple studies concluded that most qualitative research participants experience more benefits than risks. Across studies, participants reported benefitting from talking to others, reflecting on their experiences, and potentially contributing to change. Participants also expressed concerns about experiencing intense emotions, being misrepresented, and potentially being identified, which they believed could cause problems for themselves and others. Westlake and

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[1] We use the terminology "mental disability" here and elsewhere to refer to "users or former users of mental health services and other people with non-normative ways of thinking and feeling. An evolving interdisciplinary field, Mad Studies offers critical inquiry into mental health and madness in ways that foreground the oppression, agency, and perspectives" of people living with mental disabilities in the past and present, as well as in diverse cultural contexts, to challenge dominant understandings of 'mental illness' (Rice, LaMarre & Mykitiuk, 2018a, p. 270).

Forrester (2016) found that participants in their study had similar positive and negative experiences; one third reported that although interviews were challenging, no one regretted participating in the study.

Researchers who explore variable health-related topics with diverse methodologies (Leslie & McAllister, 2002; MacNeill, Foley, Quirk & McCambridge, 2016; Westlake & Forrester, 2016) contend that participants are not passive but rather active in setting their own expectations and aims in signing on for qualitative research. Further, research has been characterized as an intervention in how participants and researchers together make space to express affect and ideas, generate new insights, and imagine (and enact) communities of belonging (Cox & McDonald, 2013). Significantly, investigations of experiences of health research participation, like qualitative studies generally, tend to research "down", focusing on participants who are members of marginalized populations and orienting to changing health systems/interventions from below; rarely, if ever, is the focus of studies on healthcare providers, policymakers and other relatively powerful groups who may be better positioned to make change. Based on existing evidence, further study is warranted to advance an understanding of experiences of healthcare providers' who live with a disability as research participants.

Methods

Design

The current study is a qualitative secondary analysis known as supplementary (Heaton, 2004) or retrospective interpretation (Thorne, 1998). It involves the reuse of data to address a post-hoc issue which was not fully considered in a larger Canadian Institutes of Health Research-funded study, entitled *Mobilizing New Meanings of Disability and Difference: Using Arts-Based Approaches to Advance Healthcare Inclusion for Women with Disabilities*. One of the key objectives of this primary study was to explore representations of living with and responding to difference through multimedia storytelling workshops with women and gender non-conforming people from diverse disability communities (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015; Rice, Chandler, Liddiard, Rinaldi, & Harrison, 2018). The creation of multimedia stories or

short, first-person videos about experiences of ableism, disability and healthcare systems provides opportunities for reflective dialogue among participants and researchers. Ableism (and the related term "sanism") refers to beliefs, processes and practices which yield a particular body, mind and self: the mythical typical human being, the normative "standard" of the species (Campbell, 2009). As Rice, LaMarre, Changfoot and Douglas (2018b) elaborate, story creation fosters "evocative snapshots of our shifting, entangled subjectivities and social worlds created in equity-attentive workshop spaces. …" (p. 5). A component of the primary study was post-story creation interviews about experiences and perceptions of doing research with and as researcher-participants.

Setting and Participants

The ethically approved primary study (REB #12AP010) was supported by *Re•Vision: The Centre for Art and Social Justice*, a social science research creation centre at the University of Guelph. The centre is equipped with multiple technologies and team members with expertise in arts-based methods such as photography, performance, and videography that can be used to elicit stories with the goal of building inclusive communities through cooperative, respectful inquiry (Rice et al., 2018a; Rice et al., 2018b). The multimedia storytelling workshops took place in Sudbury, Peterborough, and Toronto. These communities were chosen based on existing partnerships between primary and preventive health and social service organizations. A total of 38 women and gender variant people in these communities participated in the primary study. For this supplementary analysis, a subsample of 17 healthcare provider participant post-story creation interviews were extracted. The creators of the multimedia stories self-identified as clinicians in either nursing, social work, or medicine. They shared that they lived with a disability, and had regular contact with other people with disabilities or differences.

Data Collection and Analysis

Six months following the creation of their multimedia stories (videos), healthcare provider participants were invited to partake in audio-recorded face-to-face or telephone semi-structured interviews about their experiences. Although the interview style varied

across the trained interviewers in each of the three locations, the shared topics of conversation included a) their experiences as creators of stories of disability and difference; b) the meaning of individualized story elements presented in their digital output; and c) the implications of their involvement in the study relative to their personal and professional lives. Sample questions included: Now that you have finished creating your story, what was the experience like for you? What are your thoughts and feelings when you viewed your story on your own? If anyone, who would you be willing to share your completed story with? What do you want other people to know or understand about disability? How has participation in the study influence how you think about yourself or others with disability or difference? How would you evaluate the process of creating and sharing digital stories?

As a research team, we made the decision to present the study findings in a manner that would be accessible to a range of audiences in our communities. To this end, we selected creative nonfiction to deconstruct and reconstruct the data into composite characters and situations (Caulley, 2008; Mus, 2012) representing dialogue, personal truths, facts, perceptions, experiences and opinions. Data from the verbatim transcriptions of the post-story creation interviews were independently read for preliminary understanding and coding of the participant experience by the first three researchers. They then met to compare, refine, and interpret the codes for the construction of distinct categories or narrative streams; these illuminated commonalties and differences among and between healthcare participant experiences. Through opting for creative nonfiction, as supported by Gutkind and Fletcher (2008), we used what is known as "compression." Compression involves combining multiple participant descriptions, situations, and experiences into a few characters to accurately and logically re/construct the narrative streams identified within the dataset. The purpose of creating individual characters to represent each narrative stream is to engage readers and resonate as "real" (Vickers, 2010). The dialogue between characters gives readers exposure to a familiar storied format to foster understanding of the lived experience of research participation. Exposure to the narrative streams in the format of a dialogical interaction, in lieu of themes or subthemes, has the potential to allow the reader to enter

into the complicated, messy, shared and diverse experiences of healthcare providers who volunteered to participate in a research study about living with disability.

Findings

We identified two distinct narrative streams across the 17 transcripts. The first stream emphasized aspects of a very positive experience, participating in an undertaking that: challenged ableist mental and physical disabilities; allowed personal empowerment and disability pride; and built and expanded understandings of collaboration and community. The alternate narrative stream, however, involved healthcare providers' more ambivalent reflections on their experiences as research participants. Given that participants experienced ableism and other interlocking forms of oppression in their personal and professional lives, these reflections indicated both powerful transformations and serious reservations. Participants wondered whether the experience really changed anything in a meaningful way; some had mixed feelings about how their stories would be disseminated; others wondered whether multimedia storytelling was a particularly accessible or effective medium for professional or public education purposes. As one participant noted, "some people find a real strength in identifying a particular disability and some of us don't."

We wove these narrative streams into a conversation between two characters, Terry and Robin. These characters are composites, created to give voice to the varied perspectives across the extracted dataset. The dialogue was built from the text taken directly, from the 17 interviews.

Terry and Robin in Conversation

Terry wonders if being in a care-giving profession, compounded by living with a disability compels her to always be on, always be up, always demonstrating that she can cope with even the unreasonable demands of her work. "It's like at work I'm supposed to be this, or I'm supposed to do this. And I actually think that is what is hurting us more than anything." She shrugs impatiently when she insists on "the right to say, I'm having a bad day."

Robin is grateful for the opportunity that the multimedia storytelling process gave her to recognize how important it is to give voice to a greater range of perspectives about the value of diagnosis in realizing personal or professional objectives. She responds to Terry's claim for the right to have a bad day by suggesting how important it is for her to be "prioritizing and showcasing marginalized voices." Robin continues, "It is really important to me to either create the art myself or create the spaces where voices don't normally get heard are able to be showcased. This is really important to me."

Yes, but then there are also "huge risks." Terry pauses to consider, "you become the story. Other people identify you as that story. You make yourself vulnerable." Terry is impatient with the notion that her life exists for the enlightenment of others, and she's thought about this more since the production and dissemination of some of the stories. She tells Robin that she needs to appreciate that "it is not easy… because most of the time people talk about very vulnerable parts of their lives or experience." Further, she observes, "the biggest problem would be the preparation and exploitation of the stories by everyone, including researchers and big institutions, medical or whatever." Terry questions, "whose interests are most served when we're recruited to participate in these kinds of projects?"

Robin acknowledges that there does need to be tight controls over how the stories are disseminated because, "for women fleeing violence or, um, dangerous living circumstances," for instance, "sharing their story might put them out there in a way that someone might recognize and then say 'Oh, I saw this person; did you know your ex did this and I saw it on the internet?'" Of course, "it can be very threatening to reveal certain personal things that might be identifiable."

"That's what I mean," Terry affirms. "I think that this is not the only way for research purposes… It is not necessary to ask people to tell their stories." She reconsiders, "Okay, sometimes it's important, but not always the best way or the necessary way to know the challenges." She nods her head, "I think there would be other ways to do that without going into detail of peoples' private lives and making them vulnerable."

Still, Robin believes that the potential benefits of sharing her story outweighs possible risk or regret down the road because "it provides a sense of empowerment in term[s] of getting that story, um, externalized for you; no longer having to carry that story with you." She pauses to find the words. "If you're constantly going over a story in your head, if you're able to get it out in a way that you feel represents it properly, then you don't have to carry it anymore." Also, it's not just the self-determining activities in the act of storytelling that matter to her. Robin explains that the experience of producing her digital story has enhanced some of her social and professional skills as well. She tries to explain to Terry that it is healing, and also "partially a way to help me talk to a bunch of almost strangers. I knew a couple of people there, but [sharing with] almost complete strangers was terrifying to me. I have pretty severe social anxiety, and it is something that I have always struggled with so… I sort of use the story, like the digital story, to help me get through that."

"That's all well and good, but of course not everyone's experience is going to be the same," Terry insists. She allows that "showing it to … complete strangers probably wouldn't be that bad to me because they don't know me. Showing it to people in my life, it just makes me feel very, very vulnerable and I'm not used to feeling like that with somebody in my life. I have a very tough front. I've not shown it to my parents. If I press the 'play' button it will be like ripping off the band-aid. I don't wanna … talk about it too much." She presses her lips together to contemplate the risks she perceives in sharing her story in certain quarters, or of having it be misunderstood. Terry explains that, "when I watch it myself, like, I understand what my intention is in making it. I can remember what it felt like; but showing it to others… even with people I'm close to, I question: 'what if they don't get it?'"

Perhaps surprisingly, Robin can empathize. She acknowledges that in telling your story, "you really are putting yourself out there. Like, there is definitely a risk whenever you're asking someone to sort of delve into their most personal experiences; opening up trauma, or in bringing up triggers of experiences... even for me," Robin admits. She continues: "Like, I left there and went home and just felt very raw for a couple of days. I wasn't one hundred per cent comfortable." But still, she also, "felt like I had a really

good opportunity to look at a part of my life [that] I hadn't looked at in years, and to sort of give myself a little bit of closure. I mean the door's not closed, but… to an extent." Terry nods. It's not that she doesn't get that, but still it is, "weird to watch it with a bunch of other people because I was not seeing it through their eyes. I was trying to imagine what it would be like for them to know my story." After all, "mental health issues have such as strong stigma still [and] I usually don't disclose my mental health history."

Robin is also someone who hasn't shared her struggle with mental disability and services widely. She may not proudly identify with her disability, but she is relieved that her "process of emptying, empt[ied] [in]to a state of wholeness." She explains to Terry that this experience was, "kind of following the thread of the story through crisis vulnerability, reclaiming… the story, and then the transformation of it; like through healing and unfolding… My story has transformed - even for myself - and I kind of uncovered these deeper layers." Terry raises her eye brows, and Robin is reminded again that her experience wasn't everyone's. Well, "the space [was] set up in a really safe way, so there were ground rules set out and that was really helpful" she concludes.

Even so. That's all well and good in the moment, but Terry is concerned about where some of the workshop participants are now, or will be, down the road when no one from the project is interested anymore in their post-story state of mind and well-being. On her best days, Terry doesn't "feel that anything has changed."

Robin challenges that view, however. Maybe in Terry's own circle there wasn't a lot to learn from the experience, but what if these stories are, "shown to people outside of [your] community, or to people who have a different understanding; they may see a different picture… They would learn to look beyond, or look at [the] ways that labels… illnesses are constructed socially and without paying attention to the person and the person's background and experience." For example, "a lot of things are really very quickly and easily pathologized and … medicalized. I think that would be something that people could learn. Especially if it is a medical community."

"Right!" Terry agrees. "It is not just like, 'oh well, it is okay, we can just give people drugs and then they'll be fine.'" She also agrees that, "a lot of people were feeling that

people in the healthcare profession are a little condescending about things, as well. I think being professional and also empathetic is kind of hard for a lot of people to balance. There is a little bit [of a] dehumanizing aspect of healthcare sometimes, which should definitely not be the case." Terry and Robin share a bit of a wry laugh because of course they know this, being healthcare professionals themselves.

But it is more than the healthcare providers that need to realize this, Terry insists. "It actually [is] a whole social issue, and people need a lot more support not only on an individual basis, such as getting access to counselling, but bigger - people receiving OHIP and more - like changing how interactions take place… as a social issue rather than just 'it is a medical issue.'" However, Terry insists that projects like this one don't necessarily advance that wider social change because multimedia storytelling "is not that accessible… When you tell a story to someone, all you need is to speak it or write it. But this requires specialized equipment."

But Robin challenges that perspective too. "In our culture, presenting information in visual ways [is] privileged with video, film, or images... [it] enable[s] more people to tap into power." Terry looks doubtful so Robin persists that reducing misconceptions around mental disability requires the use of our imaginations about its representation. Robin suggests that, "any way that the academic world of research can make itself aesthetically strong - you are really going to be heard in a larger way." Terry nods, conceding that may be the case. Both women agree, that only so many people read research articles, or at least understand their implications. These multimedia stories could reach further and deeper. Apart from whatever personal satisfaction or growth the multimedia story creators experienced by participating in the project, Terry and Robin assert that the creation of these stories are only one small piece of a strategy for wider institutional and social change.

Discussion

In this study, healthcare providers described their experience as research participants following creation of their personal stories about disabilities and differences in an arts-

based project, supported by Re•Vision. Re•Vision's multimedia workshops come from a steadfast belief in the power of storytelling, particularly within communities whose stories haven't been attended to such as healthcare providers living with disabilities. The study participants' disability stories were shaped by multiple influences inclusive of a perceived negative medical discourse about disability within healthcare. In addition, recollections of their experiences as study participants demonstrated a thoughtful understanding of their own unique contexts and a recognition of how they differed from other participants.

Healthcare providers, represented through the voices of Robin and Terry, communicated two predominant perspectives regarding their involvement as research participants: very positive and even transformative experiences, and ambivalence. Similar to other Re•Vision studies, some participants recounted that telling their story on their own terms strengthened their agency, self-determination, sense of belonging, and identity (Rice, Chandler, & Changfoot, 2016; Rice et al., 2015; Rice & Mundel, 2018). This finding aligns with published findings that support the power of sharing created stories with others. More specifically, Chandler and colleagues (2018) found that the creation and sharing of multimedia stories was instrumental in strengthening participants' politics, their community, and the disability arts sector in Ontario. As McFarlane (2011) writes: "stories are extremely powerful and have the potential to bring us together and shed light on the injustices committed against us and they lead us to understand that not one of us is alone in this world" (as cited in Costa et al., 2012, p. 86).

For some healthcare provider participants, being a research participant in the larger study validated that they, as healthcare providers who experienced some degree of disadvantage due to disability and/or working from positions of relative powerlessness within a stressed healthcare system, were a priority for the researchers. Participating in multimedia storytelling creation with, and as people living with mental and physical differences allowed them to challenge medicine's taken-for-granted ableist understandings of disabilities, experience personal empowerment and disability pride, contribute to community building, and expand their conceptions of the diversity of

human embodiments (Viscardis et al., 2018). For some, their positive experience was framed by an awareness that the new knowledge they generated through engaging in storytelling in disability affirming spaces held possibility to create new identities and connections with a larger disability community, one that was rejecting its positioning as marginal. While these healthcare providers could identify positive effects on their personal and professional identities of creating multimedia stories, they also expressed frustration with the system-wide constraints on change that they continued to confront. They spoke to issues embedded in the system— the need to be always "on," policies that inform a lack of empathy for vulnerability, and underlying beliefs about disability guiding clinical practice—that blocked and limited possibilities for change.

Other healthcare providers raised concerns regarding the personal and professional implications of participating in a study that asked them to reveal vulnerabilities. Some had never before fully processed or shared their experiences. Through story creation and sharing as a study participant, they were afforded glimpses into their inner lives, in a space that was acknowledged as a safe and respectful. What created discomfort, for some, was the potential impact of exposure, even if anonymized, in the world beyond the study that was perceived as rejecting or pathologizing of difference. Questions they asked themselves following participation included: would they be accepted; would they be othered; would they be exploited; would they make a difference. Some wondered whether others might reframe their stories as neatly-packaged narratives of resilience and recovery in which root-causes of oppression are elided and depoliticized as they sometimes are by organizations and institutions trying to peddle their services (Costa et al., 2012).

This study's findings invite researchers to take seriously Terry and Robin's conversation about the connection between telling stories and acquiring identity, agency, and community. Might stories, so powerfully told in community, wain in their poignancy after the fleeting community which surrounded their production dissipates (Rice et al., 2016)? Can their counter-narratives bear the weight of the ableism and sanism they will inevitably encounter when they are "loosed in the world" (King, 2003, p. 8)? Do storytellers, once fully connected to their stories in the creation process, feel distance

from their stories brought on by time after the workshop finishes? And, perhaps most vulnerably, do we, the researchers, have the right to claim multimedia stories as agents of change when their creators question their power?

Aware of this tension between how participants' use stories and how they can be used against them, arts-based researchers have an ethical and moral obligation to provide a safe forum for stories to be created, self-edited, and breathe on their own. To lessen the trepidation experienced by some participants with regards to releasing their stories into a public realm, researchers must acknowledge, honor, and safeguard participants' subjectivities, prior to, during, and following research completion. To ensure the safeguarding of participant stories, we work closely with participants in considering the images and details of their stories that they choose to document and share. We discuss how participants can curate their story without disclosing their identities; this may include leaving out identifiable images, having someone else narrate the story the participant wrote, or including actors in the story. Further, after the multimedia stories are created, participants are encouraged to review their consent form and, if they wish, they can revise their permission to control the release of their stories.

In contrast to the conventional practice of researchers presenting findings and results, Re•Vision researchers, committed to disability activism's longstanding position of "nothing about us without us," sought partnerships with healthcare provider participants willing to self-represent their disability stories. As a team that engages with participants beyond data collection, we regularly invite participants to co-present and co-write on their stories for diverse audiences as well as make and mobilize our own stories to make transparent our deep investments in our research (Rice et al. 2018a, 2018b). We ask storytellers to place their trust in us in order to ensure safekeeping of their stories is maintained. In return, participants ask researchers to be mindful of their knowledge dissemination activities, to consider participants' increased vulnerabilities to ableism, and to foreground policy and culture change for disability justice. After data generation, engagement with participants as co-presenters or co-knowledge translators has the potential to diffuse ableist tendencies to fixate on a person's disability and address ableist notions of disadvantage, inferiority, or something to be "fixed" or "overcome."

Thorne (1998) reminds secondary analysts of their specific ethical responsibility to those involved in the original study and their broader social responsibility to generating credible accounts. Effective, credible representation of extracted text from original transcripts may involve "creative strategies" (Thorne, p. 553) but what is not negotiable, according to Thorne, is regular dialogue with the primary researchers to solicit their advocacy on behalf of the original research participants. Collectively, we recommend that the described strategies used by Re•Vision researchers may be of value when engaging others in future arts-based research initiatives.

In the larger study, an extended partnership post-story creation, had the potential to mitigate participants' concerns around art as a dissemination tool. An ongoing researcher-participant relationship, however, raises the issue of potential boundary blurring. Dickson-Swift, James, Kippen and Liamputton (2006) argue that the duration and degree of distance between researchers and participants requires continuous negotiation to promote becoming neither too close to nor too distant, particularly when addressing sensitive topics. Given the overlaps between researchers' and healthcare participants' positionalities in our study, and our shared investments in disability rights and justice, the research findings raise another pressing question, "how can we mobilize our stories to make meaningful change in the field?" The tension underlying Terry's and Robin's conversation is an invitation for us to dialogue about how we strike a balance between the need to receive, respect, and honour disability stories with the equally urgent need to affect larger-scale change, both in healthcare and the surrounding social world.

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