

FULL-LENGTH ARTICLES

Navigating Ethical Tensions Through Critical Reflexivity: A Participatory Filmmaking Research Project With Children With Disabilities

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Keywords: Participatory videos, Youth participatory action research, critical reflexivity, cross-cultural research, inclusive research

<https://doi.org/10.35844/001c.123401>

Journal of Participatory Research Methods

Vol. 5, Issue 3, 2024

This paper illustrates the importance of critical reflexivity in guiding socially and ethically responsible participatory research through an analysis of reflexive notes pertaining to the process of a participatory filmmaking research project with children with disabilities. Within this process, numerous ethical tensions emerged in the field regarding the participation of children with disabilities, authenticity of stories shared, navigating facilitator's voice, issues of representation of child co-researchers, safety and risks associated with sharing everyday realities within the film, and limits to immediate action. The practice of individual and shared critical reflexivity among researchers, and inclusivity of child co-researchers, was central in navigating ethical tensions. This paper makes transparent the process of critical reflexivity within a participatory action research project by highlighting the ethical tensions faced, contextualizing them within cultural practices and power relations, and sharing strategies used to address 'ethics in practice.' We end by proposing practical strategies to enhance reflexive research practices in participatory work.

Introduction

Aligned with the United Nations Convention on the Rights of the Child (United Nations, 1989) and the promotion of children's right to research involvement (United Nations Children's Fund, 2007a), there has been an expansion of participatory possibilities for research *with* children (K. Freire et al., 2022), incorporating multi-method, visual, play-based, and creative methods and methodologies (Sevón et al., 2023). These participatory methods and methodologies aim to facilitate the engagement of children within research by centering their voices and creating spaces for ongoing negotiations of power differences between adult researchers and children (Montreuil et al., 2021). However, challenges are often encountered within such attempts for children's engagement in research (Montreuil et al., 2021; Twum-Danso, 2009) which are shaped by socio-political forces, including varied perceptions on the positioning and capabilities of children, especially children with disabilities (Bradbury-Jones et al., 2018; Tiefenbacher, 2022). Additionally, pragmatic difficulties within the research process — such as institutionally imposed time frames and access to monetary, equipment, and

human resources — can hinder the participation of children (Benjamin-Thomas, Laliberte Rudman, Gunaseelan, et al., 2019). Such challenges can bound the extent to which equitable participation of children as co-researchers is achieved (Benjamin-Thomas et al., 2018), and create a need for ongoing negotiation of ethically important moments, “the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research” (Guillemin & Gillam, 2004, p. 262).

Ethical tensions encompass ethical uncertainty regarding whether a situation is a moral problem, ethical distress as related to constraints on acting in ways viewed as right, and ethical dilemmas when faced with untenable alternatives (Kinsella et al., 2008). Researchers face ongoing ethical tensions in the field long after receipt of ethics approval (Canosa et al., 2018). Ethical tensions are contextually situated (Burningham et al., 2019), related to power, positionality, beliefs, norms, expectations, fears, outcomes, and responsibilities. In the context of participatory research with children that emphasizes power sharing between children and adults, such tensions may also be provoked by balancing a recognition of children as change agents while simultaneously holding a responsibility to protect their best interests (Bradbury-Jones et al., 2018; Montreuil et al., 2021). Varied sociocultural notions of a child’s positioning (Twum-Danso, 2009) and their capabilities, especially when working with children with disabilities (Tiefenbacher, 2022), or an adult researcher’s perceived responsibility to protect (Graham et al., 2014) or care (Phelan & Kinsella, 2013) for children, can contribute to ethical tensions. To address such ethical tensions, researchers have called for “living ethical practice” where “we put ourselves and our academic egos to one side and think instead of the wellbeing of those who are often vulnerable and lacking in power” (Groundwater-Smith, 2011, p. 209). When viewing such challenges as “ethics in practice,” the everyday ethical tensions faced when carrying out research (Guillemin & Gillam, 2004), attention is paid to the ongoing prioritization of human dignity (Graham et al., 2014).

Ongoing critical reflexivity is defined as a “continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also to the researcher, participants, and the research context” (Guillemin & Gillam, 2004, p. 275). It is a conscious application of an interrogatory practice of research transparency and accountability within qualitative research (Ademolu, 2023) and a key means to address “ethics in practice” (Phelan & Kinsella, 2013). Within participatory methodologies, characterized by a commitment to democratization and equitable collaboration of academics and community members through sharing and negotiation of power within research processes (Canosa et al., 2018), such reflexive practice is crucial as it attends to ethics related to the complexities of relationships driven by power imbalances (Phillips et al., 2021). Critical reflexivity is action-oriented and is not meant to be solely engaged in isolation, but rather through dialogues among all co-researchers. This is particularly important in cross-cultural research with collectives prioritizing relationships

(Liwanag & Rhule, 2021). Such a reflexive stance extends beyond analyzing the “what” and “why” of ethical moments to propelling engagement with the “now what” through conscious considerations and actions responding to ethical tensions (Graham et al., 2016).

Phelan and Kinsella (2013) point out that moving from discussing to enacting reflexivity within ongoing research practices is “easier said than done” (p. 87). Transparent accounts of ethical moments faced in the field, practices of reflexivity, and resulting decisions and actions can support scholars in mobilizing reflexivity into ethical practices (Ademolu, 2023; Graham et al., 2014). Thus, within this paper, we present a detailed, transparent account of how we utilized critical reflexivity to navigate ethical tensions faced in carrying out a participatory action research project (PAR) with children with disabilities.¹ After providing a brief project overview, we discuss a range of experiences addressing challenges in mobilizing the key principles of PAR (Benjamin-Thomas et al., 2018) and critical reflections that reveal layers of ethical complexity involved in carrying out this participatory process with children with disabilities as child co-researchers. Specifically, we explicate key ethical tensions experienced and how we employed reflexivity to navigate “ethics in practice.”

Project Overview and Processes of Critical Reflexivity

As a part of the first author’s PhD thesis, a three-phased participatory action research that utilized participatory filmmaking as the methodology was carried out with six children (aged 10–17 years) with diverse types of sensory, intellectual, and mental health challenges as identified by parents and extended community members within a rural village in India. To situate this paper, before presenting our research objectives, the first author makes transparent her relationship to this research. Researcher positioning is imperative within critically informed participatory research. It supports contextualization of research interests, makes transparent how researcher values influence the research, and prepares the researcher for navigating ethical complexities within the research process (Ademolu, 2023; Berger, 2015).

My research interests in working with children with disabilities from rural India as co-researchers emerged from my experiences in practice as an occupational therapist within community-based rehabilitation programs for children with disabilities and their families within various villages in Southern India. I witnessed many forms of injustices that children with disabilities experienced, including being stigmatized and denied opportunities to participate in everyday activities within home, school, and community environments. My practice experiences emboldened my interests to get better

¹ Children with disabilities, within the scope of this paper, encompass individuals below the age of 18 (United Nations, 1989) with “physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations Children’s Fund, 2007b, p. 2).

equipped as a community-based researcher, through pursuing graduate education, to create avenues for amplifying the voices of children with disabilities within local and global contexts as means to inform social change.

Additionally, forefronting reciprocity, an ethic of participatory research, I make transparent my relationship with the local collaborating institution in Southern India through which this research was carried out. Although this research was a part of my PhD education from a Canadian institution, I completed my undergraduate occupational therapy education at this institution. I was familiar with the community health department, the villages it serves, cultural values and practices of community members, and the local language, which is also my native language. Due to established relationships and prior experiences within this context, I was positioned as an insider in many ways, however, my childhood upbringing in an Indian city and my educational experiences from private, English speaking Indian institutions as well as international institutions also positioned me as an outsider in many ways. Navigating both insider and outsider positions supported me in working towards navigating existing inequities such as the marginalization of children with disabilities within this context, and helped me view ongoing challenges as ethical issues that required engaging in critical reflexivity.

The specific objectives of this research project were to: 1) involve children with disabilities as co-researchers² to explore their firsthand perspectives about supports and barriers to their occupational participation³; 2) support child co-researchers in envisioning what change they needed and wanted related to their everyday occupations; and 3) work with them and key community stakeholders towards addressing identified barriers and mobilizing community change (Benjamin-Thomas et al., 2021).

More specifically, six child co-researchers had an element of choice in identifying and prioritizing issues for foci within this research, and selecting the research methodology (e.g., participatory filmmaking) and methods (e.g., guided walks). As well, they were involved in the process of capturing visuals, creating narratives, participating in dialogic analysis, engaging in shared reflexivity about the research process, co-editing the film, and contributing to community dissemination efforts. All child co-researchers received ongoing training throughout the research process from the first and third authors to better support their involvement as co-researchers, which encompassed technical skills related to camera use, filmmaking and editing, as well as research-related knowledge on topics such as research ethics (Benjamin-Thomas, Laliberte Rudman, Gunaseelan, et al., 2019). This was a three-phase PAR, which included a preparatory phase, a participatory research phase,

² 'Co-researcher refers to research participants who equitably collaborate with academics within the different aspects of the research process contributing in ways that align with their skills, desires, and resources (Benjamin-Thomas et al., 2018).

³ Occupation includes the range of things people need, want, and are expected to do within their daily lives (World Federation of Occupational Therapists, 2018), and occupational participation refers to the involvement of individuals and collectives within such everyday activities and such participation is a means to promote health, well-being, and inclusion (Law et al., 1999, p. 2002).

Table 1. Overview of Research Phases and Activities within this Participatory Action Research

Phase 1: Preparatory Phase	Phase 2: Participatory Research Phase	Phase 3: Action Phase
Strengthening local collaboration with local institution and institutional collaborators through in-person meetings addressing roles, plans, and project values	Rapport building amongst researchers, child co-researchers and extended community	Proposing solutions for identified issues
Identifying local volunteers	Identifying and prioritizing research foci	Creation of action teams
Identifying a local village	Choosing a specific participatory digital methodology to guide the research	Community-based programming
Recruitment of child co-researchers	Ongoing training of child co-researchers	
Selection of equipment for utilizing participatory digital methodologies	Video making through dialogic analysis and shared reflection	
	Community disseminations	
	Wrapping up and concluding field activities	

Note: Contents of this table are adapted from Benjamin-Thomas, Laliberte Rudman, Gunaseelan, et al., 2019

and an action phase. An overview of activities carried out in each phase are outlined in [Table 1](#). Phase 1 was initiated by the first author prior to the engagement of children as co-researchers. Activities in Phases 2 and 3 were carried out with child co-researchers, with the action phase also involving local community members.

The first author spent approximately eight months in the field and conducted approximately 35 group meetings with child co-researchers. The third author, a photographer by profession, helped co-facilitate many of these meetings. All meetings were conducted in the local language, Tamil, as both facilitators were fluent in Tamil, and the recorded meetings were translated from Tamil to English by the first author with support from a local retired teacher. A detailed description of project phases, activities, and pragmatic challenges are discussed in Benjamin-Thomas et al. (2019).

Creation and Analysis of Reflexive Notes

The first author engaged in reflexivity throughout the project to address ethical tensions and inform ongoing methodological decisions. She maintained a reflexive journal, starting in the preparatory phase and continuing through the rest of the project. Engaging in reflexive note taking was a means for the first author to engage in on-going reflexivity regarding how her interests and positionality influenced decisions made within this research process, relationships, and other processes and, in turn, shaped the project's outcomes. These reflexive journal entries were handwritten and later typed into a Word document under organized themes that were highlighted within the written notes. These themes were based on ongoing needs and tensions faced within the process (e.g., power-sharing, flexible timeline, cross-cultural research, realities on the ground, need to de-rail from "ideal" PAR process, inclusion, collaboration, etc.).

Table 2. Guiding Questions that Supported Shared Dialogic Reflexivity

Questions	
Shared Reflexivity: Facilitators	What went well today? What did not go well? What could we change for next time? What were some challenges? How has the process been so far? Do you feel like we are making progress with this? Do you feel like what we are doing thus far has been participatory? What have the children gained so far? Do you think they are leaving this project with specific skills? Is there anything we could have done better? Are there any tensions with collaboration so far? Do you feel like this project has the potential to bring about change? What kind of change? Why and why not?
Shared Reflexivity: Child Co-Researchers	Did you like the activities today? Are there any activities you didn't like today? Anything you would like us to change for tomorrow? Did you feel like you contributed a lot to this project and how? How could we have done this project better? If we were to re-do this next year, what would you like changed? What do you think are the outcomes of this research project? What changes do you think will come about from this research project? What was the best part of this project? What was not so nice? Did you learn anything new from this project? Were there any challenging parts to this process? Do you feel like anything has changed within yourself after participating within this project?

She also engaged in shared dialogic reflexivity, a process when two or more people engage in reflexivity together through conversation. This occurred once every few meetings with her co-facilitator (the third author) for approximately 10 sessions, with each session lasting 20–30 minutes. These sessions involved collaboratively identifying and addressing on-going challenges to enacting ideals of PAR (Benjamin-Thomas et al., 2018). This dialogic reflexivity sessions, informed by Freire's (1993) critical pedagogy, aimed to utilize an egalitarian approach to deepen shared understanding of the situatedness of ongoing experiences within the research process (Farias et al., 2019). The facilitators also aimed to enact a relational, collaborative process (Liwanağ & Rhule, 2021) that involved sharing tensions and talking through various potential means of navigation. These sessions were audio-recorded and later transcribed by the first author for analysis. Further, the facilitators continually engaged in shared dialogic reflexivity with child co-researchers, which was embedded within their 35 sessions of ongoing discussions. These sessions utilized the SHOWed approach⁴ to support data generation and analysis and also supported child co-researchers in engaging in reflexivity to explore shared experiences, identify challenges to participation, address power differentials, and navigate ongoing ethical concerns within the research process. Visuals captured by child co-researchers as part of ongoing data generation were used to facilitate dialogic reflexivity. For example, when child co-researchers captured visuals that had specific identifiable information, it facilitated shared reflexive dialogue among the group on issues of confidentiality and its consequences for public dissemination, as well as ways to address these issues. An overview of questions discussed among facilitators as well as with child co-researchers are provided in [Table 2](#). These open-ended questions provided a starting point to facilitate reflexive dialogue, which included identifying and discussing issues, tensions, and challenges, attending to their causes, and considering how to address these issues.

⁴ The SHOWed approach encompassed questions like, what do you *see* here? What is really *happening* here? How does this relate to *our* lives? Why does this problem, concern, or strength *exist*? What can we *do* about it? (Wang et al., 2000).

The analysis process of addressing reflexive notes and dialogue was initiated when the first author engaged in journaling as she noted emerging themes in relation to ethical tensions within the research process. This analytic process continued when she transferred her written journal entries into a typed Word document, where she further identified new themes and refined existing themes (Saldaña, 2016). Additionally, all transcribed shared reflexivity sessions were independently coded (Miles et al., 2014) by the first and second author (thesis supervisor) to identify additional themes related to ethical tensions. Themes were further refined through on-going dialogue between the first two authors.

Critical Reflexivity: Navigating Ethically Important Moments in the Field

In this section, we discuss identified themes addressing ethical tensions that emerged from our analysis. Specifically, we discuss striving for participation, navigating authenticity and risks, navigating facilitator's voice and representation of children with disabilities, and facing limits to enacting immediate action. Within each theme, we highlight challenges and tensions, contextualize them, and share strategies used to manage "ethics in practice." We do not assert that these strategies represent the "right" resolution of ethical tensions, but rather attempt to be transparent about how and why they unfolded and what we experienced as flowing from them. Below, the terms "I" refer to the first author; "we" and "facilitators" refer to the first author and third author; and child co-researchers are identified using pseudonyms.

Striving for participation. "Participation" in research processes ideally refers to children being supported in their desired forms of research involvement (Hart, 2008). Within the context of participatory action research, such "participation" extends to children being involved as co-researchers through opportunities like choosing a topic of interest and research methodologies and methods as well as involvement with data generation, analysis, and dissemination (Benjamin-Thomas et al., 2018). This co-researcher positioning strives to enact ethical research practices through challenging power differentials within the research process, as co-researchers are given the opportunity to make key project-related decisions in contextually relevant ways. Within our research, we worked to create a space for children with disabilities to be co-researchers and direct various aspects of the research process. For instance, child co-researchers made decisions regarding meeting details, such as location (e.g., meeting in the fields), time, and snacks, which were informed by their interests and way of being within their communities. As well, they made the decision to create a film as a group rather than as individuals due to a collectivist lifestyle within that context and decided upon specific topics and content for the film such as garbage accumulation, deforestation, substance abuse, and violence (Benjamin-Thomas, Laliberte Rudman, Gunaseelan, et al., 2019).

As we worked towards facilitating equitable participation, we faced numerous ongoing challenges that presented as ethical moments. These tensions were related to having a closed group of children identified as having disabilities versus opening the group to all children, addressing the inclusive needs of child co-researchers, and instances of initial resistance and mistrust from children and community members.

As Freire (1993) highlights, the first step towards social transformation is the unveiling of oppression by people experiencing oppressive situations. This project sought to work with a group of children with disabilities⁵ in a village in rural India as the goal was to listen to first-hand perspectives of their everyday experiences as a means to raise critical consciousness and address social change. Several studies within the Indian context discuss the presence of negative attitudes and stigma towards children with disabilities that shape their everyday experiences of inequity (Edwardraj et al., 2010; George et al., 2014). These studies predominantly center the perspectives of parents, teachers, and/or other service providers, and rarely those of the children themselves. To work towards social transformation addressing needs of children with disabilities, we felt it was imperative to involve children with disabilities as co-researchers (Njelesani et al., 2022).

However, children from the community who were not identified as having disabilities also wanted to be involved in project activities. For instance, during the first group meeting with child co-researchers, many children outside this group from the local community were looking through a window into the meeting room, constantly requesting to join in the activities. These on-going requests were likely connected to this project being initiated during the summer when all children were on school vacation. Moreover, most children within this context were seeing cameras for the first time and genuinely wanted to use them. It also appeared that they were excited to see two “outsiders,” and wanted to be part of this event. Moreover, this community practiced a collectivist way of life; the child co-researchers wanted their friends with them and parents wanted siblings to accompany child co-researchers for safety and support.

We faced an ethical dilemma in wanting to be inclusive of all children to respect the collectivist way of life while trying to address concerns regarding whether the inclusion of children not identified as having disabilities would constrain the space for child co-researchers to express their viewpoints. This tension was situated in a context within which children with disabilities have been shown to be viewed as lacking abilities and as lower status (Wolbring & Ghai, 2015). Within the initial sessions, in which other children and adults entered, we experienced this tension. For instance, Shivam [pseudonym, child co-researcher] was initially enthusiastic about the topic of recycling and

⁵ The positioning of children within the two groups “children with disabilities” and “children without disabilities” is for clarity purposes only. We acknowledge that both groups cannot be viewed as homogenous, and children within these groups embodied a range of experiences and responses.

garbage sorting that he brought forward to the group, but when his friends joined the discussion, he took a back seat and said, “Let’s go to the shop.” Additionally, adults from the local community also wanted to step into sessions, and we needed to embrace flexibility and cultural humility while navigating how the presence of such adults could also have constraining, and sometimes potentially damaging, effects. For example, an older gentleman from the community who was listening to one of our sessions called one of our co-researchers “mental”/“acting mental,” which brought the co-researcher to tears.

We wanted to facilitate the full engagement of children with disabilities as co-researchers, a promise that PAR embodies (Benjamin-Thomas et al., 2018), through creating a space for children with disabilities to take lead in the project. While we sought to acknowledge and embrace the collectivist values of the context by involving children not identified as having disabilities, as well as extended community members within the initial meetings, this created a space for further stigmatization and silencing of voices of children with disabilities. To address this ethical tension, we had to navigate how to continually co-create a space that not only amplified the voices of children with disabilities but also positioned them as leaders within the scope of this work.

Some of the initial sessions were held in an accessible location by the road and community members who were passing by wanted to know what was going on. These adults often wanted to be a part of the conversation and speak on behalf of the children with disabilities. We felt a need to think of ways to address who was attending by changing the session locations. To address the interruption of adults, child co-researchers often took the lead in changing meeting locations during meetings to minimize such interruption. For example, Shivam [pseudonym, child co-researcher] shared, “Maybe have it [the meetings] in a room?” and Karthi [pseudonym, child co-researcher] followed up by suggesting, “We can maybe meet here and then decide where to go as a group, okay?”

Embracing existing cultural collectivist practices, and responding to co-researchers’ requests to involve other children from their community, all children were invited to join in the rapport-building activities during all sessions. Within those activities, child co-researchers were intentionally named as team leaders, which provided a good way to start building rapport within the small group as well as the extended community. As the sessions continued, we created a pattern where we had a large group of children from the community for ice breaker games in every session. Once these games were over, we split into smaller groups and worked with child co-researchers in the participatory filmmaking process. On some days, we circled back as a larger group and wrapped up with large group games and snacks. Given parents’ requests, siblings of child co-researchers were often present in small group sessions with child co-researchers as a means of support. We communicated

with the siblings about project objectives and reminded them that we wanted to forefront perspectives of child co-researchers, and the siblings were largely supportive.

The continued involvement of children not identified as having disabilities even in the preliminary ice-breaker activities came with other ethical tensions, such as the reproduction of discriminatory behaviors and deficit-oriented disability discourses as they often called child co-researchers by their impairments versus their names, and acted in ways that created marginalizing situations for children with disabilities. For example, during group introductions when it was Velu [pseudonym, child co-researcher]'s turn to share his name, some other children yelled out "Oomai," meaning deaf and dumb in Tamil. They made derogatory sounds in imitation of Velu's voice when he attempted to speak. Further, when cameras were introduced for an activity, children without disabilities snatched cameras away from child co-researchers saying, "He does not know anything," or "I can take a better picture than him." We had to address these ethical tensions by calling these behaviors out, and sharing that what they were doing was hurtful. As such, when collaborating with vulnerable children, "We need to ensure that we don't simply replicate the vulnerabilities and disadvantages that they experience in other areas of their lives" (Bradbury-Jones et al., 2018, p. 88). These moments reflected the everyday experiences of children with disabilities within that context, which child co-researchers came to speak about within their participatory film.

To further respond to these ethical moments arising from negative comments and discriminatory behaviors related to disability, we inserted a learning component within large group games that aligned with the principles and commitments of PAR to address issues of power and equity within the research. For example, during the ice breaker games, all children had a chance to approximate the experience of what challenges to communication with a hearing impairment felt like (one of the child co-researchers had a speech and hearing impairment) through playing a communication game using headphones with background white noise. Additionally, we collectively established ground rules within the group to deal with teasing behaviors. These sessions supported all children in understanding what was offensive, and some of them started identifying and addressing such behaviors in subsequent sessions. For example, while engaging in a group activity, one child from the community called out a peer's behavior, stating, "Vijay [pseudonym], is calling Shivam 'glasses, glasses' instead of Shivam."

To facilitate the full inclusion of children with disabilities as co-researchers, impairment-specific needs had to be addressed. Given a lack of resources within a rural Indian context combined with socio-politically shaped barriers, such as stigma associated with disability, it was a challenge to accommodate some child co-researcher needs. One such example was related to challenges faced in supporting optimal participation of Velu [pseudonym, child co-researcher] who had a speech and hearing impairment. We could only

communicate with him through actions and lip reading, which worked for discussions encompassing “yes/no” and “what” questions. However, when we needed to engage in deeper discussions encompassing “why” questions, it was hard to effectively communicate with Velu and support him in his role as co-researcher. Sign language was not an option, as neither ourselves nor Velu were trained. Efforts to use written communication did not work as he kept copying written notes, rather than reading and responding to them. Throughout the process, we engaged in dialogue regarding strategies to optimize communication with Velu. For example, we developed a strategy in which one of us situated ourselves at Velu’s side and used actions to communicate to Velu what others were saying. Additionally, we later realized that Velu had a hearing aid that he refused to wear. His mother shared that this refusal was both because other children made fun of it and due to concerns that it might get lost as other children often threw it around. Even when Velu was convinced to bring his hearing aid to meetings, he chose not to wear it. Velu’s refusal reflects how he had the space to reassert power over our persistence in convincing him to bring his hearing aid and requesting him to wear it. This has led me to realize how we as researchers can implicitly attempt to enact our position of power to facilitate full participation of co-researchers, a principle of PAR, even when co-researchers might not be fully comfortable or interested due to varied reasons and experiences. To further address the ongoing communication barrier, we also tried strategies such as including Velu’s sister to help with communication in addition to using written forms of communication. We also attempted to brief Velu about each day’s agenda by meeting him at his house prior to meetings, where he was comfortable wearing the hearing aid. Unfortunately, we came to realize, along with his mother, that one of his hearing aids was not working and his parents could not afford to have it repaired immediately. Despite our attempted strategies and Velu’s presence at most meetings and in capturing videos, it was an on-going challenge to support his engagement within shared dialogue and reflection processes.

In another example, we worked with Arun and Kumaran [pseudonyms, child co-researchers], siblings diagnosed with intellectual disabilities. Due to financial difficulties within their family, they stayed in a residential hostel for children with disabilities through the year. We had the chance to work with them during their annual two-week visit home but encountered challenges in trying to support their participation alongside other children, even within games. The brothers repeatedly articulated, “My teacher would hit me if I play.” Their previous experiences of limited opportunities for sustained activity participation, along with our use of research-related activities that necessitated sustained attention, further impacted their participation within the research process. Additionally, listening to their hostel experiences of isolation and a lack of opportunities for participation in meaningful occupations positioned us in an ethical dilemma in trying to explicate the issues of isolation, lack of occupation, and injustices within the context

of their everyday lives. We worked to be optimally flexible, meeting Arun and Kumaran as a separate group along with their sister by their house, which they preferred. We started with rapport building and activities they enjoyed. We adapted our research-related activities to support participation. For example, our conversations were alongside physical activities like hiking. Over time, we were able to establish rapport, but by the time relationships were established, Arun and Kumaran returned to the hostel. Although they learned how to use cameras and capture videos, they were not involved in the filmmaking process alongside other co-researchers. We also attempted to discuss the hostel experiences shared by child co-researchers with their parents, given the ethical distress these provoked for us. However, their parents expressed that their children received the basic necessities, such as three meals a day in the hostel, which were not possible at home given financial constraints. We learned that ethical dilemmas and tensions in the field cannot always be resolved, with some situations bringing additional layers of ethical questions for consideration and reflexivity.

Although child co-researchers' participation within this research, as well as reciprocity with extended community, developed gradually over the course of this work, there were aspects of initial resistance to child co-researcher participation from parents, child co-researchers themselves, and other community stakeholders. Participatory action research is a relational process (Benjamin-Thomas et al., 2018) and such resistance brought ethical tensions. For example, during the project's initial weeks, some parents seemed cautious and did not send their children to activities in locations away from their homes even though they were within the same village. They preferred having them within eyesight. In other instances, parental beliefs about certain activities and places prevented them from sending their children to meetings on some days. For example, some parents did not like children climbing trees, or walking through the fields due to the presence of venomous snakes, or meeting in places rumored to have ghosts. Additionally, certain days and times, informed by religious beliefs and practices, were considered as "not a good time" by parents for children to leave their homes. This type of information was communicated to us on an ongoing basis, and we worked to adapt sessions based on parental requests. As such, PAR processes need to attend to reciprocity by addressing broader contextual issues that influence trust and relationships with the community (Maiter et al., 2008).

Suspicion and potential mistrust were also seen in some instances among child co-researchers and extended community members. For example, when the project occurred, there were some issues related to child trafficking within neighboring communities that had been shared on media, which had created fear among children and parents within this community. For instance, Velu [pseudonym, child co-researcher] stopped attending meetings regularly and we later found out from his mother that she had told him about child trafficking and not to accept snacks from strangers as they will take him away. She also mentioned that this was a likely reason for his sudden change

in participation. At times, we were approached by community members who inquired about our work within the community, which was interpreted as efforts to ensure safety. Our positioning as insiders within this context in some ways, with sameness in relation to ethnic background and native language, informed some of our presumed assurances of access and rapport with the community (Ademolu, 2023). However, these presumptions were challenged in the field through instances of resistance and mistrust and required us to continually engage in reflexivity as we navigated positions back and forth within the insider-outsider continuum (Potts & Brown, 2015).

To address these ongoing challenges, we prioritized building relationships within the PAR process (Maiter et al., 2008), and over time, parents and community members gained trust and were increasingly supportive of the children's participation. To enhance parents' feelings of safety, we visited the households every day at the start and end of the meetings to communicate meeting plans. We also made accommodations with meeting locations and provided snacks based on parental requests. As well, once community members learned that this project was carried out in partnership with a local health care institution that they were familiar with and trusted, their questions about us being in their village were clarified. Moreover, relationships established with child co-researchers over time, including prioritizing their interests, created a safe space for their involvement. They were always looking forward to these group meetings and expressed that they "liked learning to use the camera," "us coming to their village," and "everything" within the scope of this work.

This participatory process took longer than our anticipated timelines, reflecting how the principle of equitable collaboration within PAR was mobilized (Kemmis et al., 2014) in that the pace of the research was led by child co-researchers as well as needs from parents, and not dictated by external research agendas and timelines. For instance, child co-researchers decided that some days encompassed only games with no discussions, while other days were mostly discussions and video making. We realized through engaging in reflexivity that respecting the pace of the children and intentionally working to be patient and flexible was essential to facilitate full participation of child co-researchers (Wickenden & Kembhavi-Tam, 2014).

Navigating authenticity and risks. During the scope of this work, we faced ethical tensions related to the authenticity of stories shared by child co-researchers, and how the sharing of their realities could have consequences for child co-researchers' safety.

This research aimed to create a space for children with disabilities to share their experiences of participation in everyday activities. Disability scholarship addressing the experiences of children with disabilities within rural Indian contexts predominantly highlights their experiences of marginalization arising from how their impairments are socially understood and addressed (Anees, 2014; George et al., 2014; Ghai, 2002). Therefore, an implicit assumption that underpinned this work, informed by literature, was that child co-

researchers would center their impairments when speaking about their everyday experiences. However, the most common issues initially brought forward by child co-researchers were community issues — namely, garbage accumulation and deforestation, which persisted for weeks as foci for discussion. Initially, we faced persisting difficulties in eliciting group discussions about impairment-related challenges that child co-researchers faced, and we were constantly trying to understand whether these community issues were really of importance to child co-researchers or if they were surfacing because they were part of the school curriculum or were related to the location of meetings (i.e., near a garbage sorting area). This was situated as an ethical tension as we were questioning the authenticity of discussions. However, through engaging in reflexive dialogue, we realized the influence of unconscious assumptions informed by our positioning as adult, able-bodied individuals, holding experiences of working in healthcare settings with children with disability-related impairments. As well, dominant discourses on experiences of marginalization within disability scholarship had also shaped our expectations about relevant topics of discussion. As Ademolu (2023) highlights:

Not only is it incumbent on the researcher to acknowledge how their biases, presuppositions, values, interests and idiosyncratic predilections influence and coalesce with methodological decisions and knowledge claims. They must also continuously challenge these, especially as they are renegotiated and modified during interaction with participants. (p. 3)

The interactions with child co-researchers and shared reflexivity helped us forefront and challenge some of our underlying presumptions that disability-related experiences would be the central focus of the research project. Additionally, through ongoing reflexivity, I realized that child co-researchers utilized the PAR space to take on positions of power to voice and enact social change within their community, which could have been hindered if child co-researchers were only allowed to speak about their experiences of marginalization.

We intentionally presented questions that urged child co-researchers to speak about challenges faced at both the individual and community levels. Although we heard, over time, about issues child co-researchers faced on an everyday basis individually and collectively (e.g., marginalization within schools, teasing and bullying), we also learned that the child co-researchers were concerned about addressing community issues as these issues kept recurring even after meeting spots were changed. Moreover, the lived realities of these community issues were brought to light when the child co-researchers took the facilitators to different spots within their village for capturing videos and discussed the burden for them and their communities. As Kellett (2011) reminds us, when research interests emanate from children, and their understandings of their worlds and subcultures, no adult will

be able to bring out the same richness of this knowledge. In turn, these experiences challenged us to think through, reflect, and expand our pre-understandings of issues to be addressed through the project.

Furthermore, participatory filmmaking has been designed as a tool that community members can use to document and critically engage with ongoing social issues, and ideally involves creating a space for participants to express deeply personal thoughts and experiences of oppression (Benjamin-Thomas, Laliberte Rudman, Cameron, et al., 2019; Mitchell et al., 2012). Within this project, we faced ethical dilemmas considering the consequences for child co-researchers in sharing their realities that exposed systemic forces of inequities and its potential to affect their safety. For instance, when we started this project, we wanted all child co-researchers to be from one community because of their shared experiences and as means to mobilize community change in that one context. However, as we engaged in reflexivity when thinking about avenues for community dissemination of the created video, we realized everyone in this community might know the child co-researchers who created the videos. There were only a few schools within this village and a handful of teachers in each school. Everyone knew who the teachers were, and within the film, child co-researchers shared how teachers also contributed to their experiences of marginalization. Furthermore, community members, including teachers, were familiar with the involved child co-researchers. If we disseminated this video to the teachers, there could have been breach of confidentiality.

Indeed, there were no easy answers, but Kellett (2011) points out, “as with all initiatives that involve children, safeguarding and protecting them has to be a top priority” (p. 213). When we were listening to meeting recordings to create a base audio-narrative for the film, we were cautious so that no personal and identifying issues were included, such as location details, names of schools and grades, or personal family issues. This ethical tension was also addressed through ongoing discussions with child co-researchers about what could and could not be shared in the film, as well as where the film could be disseminated. We specifically engaged in reflexivity with child co-researchers discussing whether their parents would get angry when issues of substance abuse in their families were discussed and depicted as a problem, and how schoolteachers might react. Karthi [pseudonym, child co-researcher] shared, “If we show it to the teachers, they can say, ‘These kids are here just to blame us and complain about us.’ They can also fight, saying ‘Why did you make us look so bad?’ And they may not include us in school... and also say ‘go join another school.’”

Through on-going discussions, we collaboratively made decisions on what to remove from the film’s narrative when editing the film based on child co-researcher preferences, and where and with whom the film would be shared. We collaboratively decided that it was safe for the community in-person dissemination of the film to happen only among close and extended family members of the children and neighbors they wanted to invite. We

also decided to move forward with a dissemination for village leaders and for service providers from the local collaborating institute, and not a direct dissemination to teachers within that context. Through these in-person community disseminations, child co-researchers positioned themselves as responsible citizens and social actors by not only addressing matters affecting them at the individual level but also matters affecting their communities. They shared their views about issues of deforestation, violence, substance abuse, and garbage disposal in addition to their everyday experiences of occupational marginalization (Benjamin-Thomas et al., 2021).

Navigating facilitator's voice and the representation of children with disabilities. Ademolu (2023) shares that critical reflexivity:

Implores researchers to think earnestly about attribution and representation of who speaks “when,” “where,” “how,” and “for/to whom?” As such, we must consider how “voice” is afforded, withdrawn, distorted and expressed by/for participants, as well as how, to what degree, and upon which platform, researcher/researched “power” (e.g., to frame, clarify, revise and represent narratives) is appropriately shared. (p. 18)

Within this participatory film co-created with child co-researchers, we faced ethical tensions in trying to balance my voice with the voices of child co-researchers as well as addressing dilemmas in relation to the representation of child co-researchers within the film. As we produced and disseminated the participatory film, its structure changed to include an introduction narrated by me, serving to contextualize the film and the process used to create it. This introduction was not included in the film during initial community dissemination. However, I was physically present to contextualize this work. Audience members suggested that it would be good for me to add content about the filmmaking process within the film to allow it to stand on its own. I circled back to child co-researchers and discussed the idea of adding this narrative about the process to the film, and they agreed as they wanted me to be in the video with them.

I initially did not foresee including my voice in the film as I was wary of power differentials and did not want my voice to be forefronted within the video. However, when child co-researchers and parents wanted the film to be shared online, it made sense for contextual information about the process to be added to the film. After reflexively engaging on how I could work with this feedback and not distance myself from the process, I circled back with the child co-researchers and we collaboratively captured footage about the process of creating the film.

In trying to emphasize the authentic voices of child co-researchers within the scope of this work, an ethical dilemma we constantly navigated was tensions in relation to the representation of child co-researchers as children with disabilities within the film's introduction. Although child co-researchers expressed how the community did not accommodate for certain impairment-

related needs, they never identified themselves as having a “disability.” For example, they situated their issues of teasing and bullying within larger contextual issues of discrimination and violence experienced among many children within their community along various types of difference such as being tall, short, dark, fair, or if their name sounded different (Benjamin-Thomas et al., 2021). Some questions we wrestled with were: Do the viewers of the film need to know that the children involved were identified as having a disability? Would that affect child co-researchers in any way as they did not identify themselves as having a “disability?” These questions were particularly significant as the literal translation of the word “disability” in Tamil was not seen positively within their community. After initial community disseminations, some viewers suggested that the film would benefit from making more explicit that it was carried out by children with disabilities for the message to be more powerful, particularly in challenging negative stereotypes. These suggestions created an ethical dilemma regarding what was important. Did we want the film to be more powerful? More specifically, mobilizing social transformation through challenging dominant negative assumptions on the positioning of children with disabilities as incapable and of lower status might be a priority (Wolbring & Ghai, 2015), but should this occur if it came with the cost of further perpetuating stigma for the child co-researchers involved in this work? I also wondered if it would change the narrative shared by child co-researchers in anyway. I had a conversation with child co-researchers about this and discussed whether they were comfortable with me sharing about their “impairments” in the film’s introduction, which they were. I was not comfortable using the word “disability” in Tamil and attributing that identity to them within our discussion or the film’s introduction. This discomfort with the Tamil word disability was based on my own experiences speaking Tamil in my own household and in living and working within this and other similar contexts where there was stigma attached to this term. I wrestled with questions about word choice even though the introduction was created in English. Would it be “children with disabilities” or “special needs” or “additional needs?” This tension in word choice, especially when constructs need to be translated into local languages, is something I continually reflect on as I continue to engage in cross-cultural research work. What was included in the film’s introduction was that this project was carried out with children identified by their community as having special needs. I felt like its literal Tamil translation did not carry stigma like the word “disability” did, while at the same time highlighting that the children who created the film had some types of impairments.

Facing limits to enacting immediate actions. I began this project hoping for social transformation, which is consistent with critical/transformational research values (Ponterotto, 2005). However, during the process, relationships were established with child co-researchers who had various immediate needs. We grappled with limits to our abilities as researchers to act in addressing immediate change for the children involved within the project.

Most child co-researchers had basic needs that were not being met, such as housing, electricity, assistive devices, adequate food, footwear, or barriers to schooling. Although issues related to occupations (i.e., how children navigate their participation everyday activities) was the focus of our study, we felt a tension in terms of whether it made sense for the project to focus on occupational participation given the struggle for more immediate needs. We also struggled with not being able to provide quick fixes to individual issues experienced by the child co-researchers, but rather focusing on raising awareness of collective issues and mobilizing social action. For instance, a child co-researcher had stopped going to school a few years ago, and during our conversations he had shared that he wanted an education but did not want to go to school again. Another child co-researcher was on the verge of being dismissed from school because of his performance, which his parents often discussed with us. All of these children were interested and engaged within the scope of this work, but we were constrained in our abilities to address individual educational needs. It created within us a sense of sadness and burden knowing that this work has the potential to stir community change, but this change may not address the child co-researchers' immediate needs. As such, the emotional burden associated with carrying out a PAR has been highlighted as complex, and as spreading across all research team members (Klocker, 2015).

Ways Forward in Enacting Researcher Reflexivity

This manuscript makes apparent the need for, and potential of, on-going critical reflexivity to navigate ethical tensions within participatory and transformative forms of research. Continually engaging in reflexivity allows researchers to exhibit transparency, sincerity, and in turn, integrity in guiding ethical research practices (Appleton, 2011; Guillemin & Gillam, 2004). Within this participatory filmmaking research project, individual as well as shared dialogic reflexivity supported facilitators and child co-researchers in thinking through and negotiating ethics in practice.

In supporting the call to become a reflexive researcher (Phelan & Kinsella, 2013), we forward ideas that researchers can utilize, and build from, based on their contexts to embrace reflexivity within research practices. We specifically highlight the processes used within this participatory filmmaking project, which included researcher journaling, dialogical shared reflexivity, and visual tools to guide reflexivity with co-researchers.

The most common method for researcher reflexivity is through maintaining a researcher journal, where a log of ideas, observations, readings, apprehensions, joys, and surprises within the research process and outcomes are noted (Newbury, 2001). Within this project, I maintained a researcher journal containing notes about the context, process, challenges, tensions, and supports as well as my emotions throughout the research process. These notes were often written after I returned from the field as it was impossible to write when working alongside child co-researchers. Although I tried to write notes after every meeting and situation encountered within the project,

there were many instances when it was hard to write thoughts down — especially in moments when the process was challenging or emotionally burdensome to reflect on. One such example was when I was wrapping up the project in the field with child co-researchers. I struggled with bidding farewell to the group while also wondering whether this project did good for the child co-researchers involved. In turn, I was not able to write many of my thoughts down during that time as there was immense sadness when leaving, letting go of relationships, and thinking about some unaddressed struggles. As such, engaging in reflexivity when addressing deep emotions within research processes is often challenging, as research training typically denies the presence or salience of emotional reactions (Russell & Kelly, 2002). Through ongoing reflexivity after project completion, I still grapple with tensions about built relationships that had to be let go of. This work was carried out within a context that I had to leave after project completion, and with reciprocity being central to this kind of work, I still wonder about how an ethical PAR can be carried out within cross-cultural contexts.

Engaging in dialogical reflexivity further supported this reflexive process. This process of shared reflexivity can be with co-facilitators, collaborators, participants, or anyone considered as critical friends, who “fully understand the context of the work presented and the outcomes that the person or group is working towards” (Costa & Kallick, 1993, p. 50). Within this project, my co-facilitator and I engaged in shared dialogic reflexivity with each other at different points during the process. We acted as critical friends by listening to each other, questioning our understandings, interpretations, assumptions, and expectations as means to progress with the research in an ethical manner (Appleton, 2011).

Another effective way for engaging in reflexivity is by using photos, creating visual diaries (Newbury, 2001) or reflexive drawings (Calvo, 2017). Visuals often complement written notes and support the recall of lived experiences (Calvo, 2017). Although we, the facilitators, did not personally use visual diaries, shared reflexivity with child co-researchers included visuals. For example, when in the process of exiting the field and saying goodbyes, some photos captured by the group during this process were shared with the child co-researchers as a video as well as a book. These visuals supported dialogic shared reflexivity about their experiences within the process and reminded child co-researchers of their participation within this project, the various activities they engaged in, locations visited, relationships built, skills acquired, challenges faced, and memories made. Furthermore, when making goodbye notes, child co-researchers drew images of them holding the first author’s hand, which visually portrayed how relationships were central to their experiences within the participatory filmmaking process as well as their emotions.

Engaging in reflexivity is a form of research in and of itself, where the research process and researchers’/co-researchers’ selves become the objects of research (Newbury, 2001). Participatory and transformative forms of research

embody sharing and negotiation of power, with participants considered as co-researchers and researchers simultaneously considered as participants. By looking inwards and drawing out reflexive accounts of experiences, an often-hidden aspect within published manuscripts (Newbury, 2001), there is added richness, honesty, and research authenticity (Appleton, 2011). Indeed, engaging in critical reflexivity can support the collective responsibility to engage in socially and ethically responsible research practices (Ademolu, 2023).

Submitted: September 13, 2023 EDT, Accepted: March 12, 2024 EDT



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