

CHAPTER 2

Vulnerable Agencies: A Performative Research Assemblage on Dis/Ability

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Abstract: In this article, I describe an artistic research process stemming from my work as a dance pedagogue in disability services. Describing and reflecting on the process that led to the artistic part of my research, a performance installation at the New Performance Turku festival in Finland in 2018, I aim to develop a nuanced and ethically sensitive understanding of diverse and vulnerable agencies in the boundary areas between arts, research and social care. The ethical dilemma I address in this article concerns the paradoxical nature of situated and shared vulnerability. I reflect on how the different vulnerable agencies have been negotiated in my research project, and what ethical insights this negotiation brings forth. Methodologically, my research is situated at the intersections of artistic and performative research, post-qualitative inquiry, and feminist ethnography. Based on methodological experiments and theoretical discussion, including the ethics of care, vulnerability, dis/ability and ableism, I consider the complexity of participation, power relations and decoloniality in artistic research. Through the example of my research project, I describe how frictions between different contexts in the arts, academia, and social care become tangible in light of the social-material-discursive phenomenon of dis/ability. In the conclusion I suggest that we should continue to reflect on the complexity of the possibilities of participation, problematising artistic and academic practices, in which disabled people's agency is determined and mediated by abled people.

Keywords: vulnerability, dis/ability, performative research, artistic research, agency

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You feel supported when you wake up
You feel restricted when it rains
You feel supported when you walk in the mountains
You feel restricted when you are in a hurry
You feel supported when you get your salary
You feel restricted when you don't understand
You feel supported when the sun shines
You feel restricted when it is nighttime
You feel supported when someone calls you
You feel restricted when you are cold
You feel supported when someone holds you tight
You feel restricted when someone holds you tight
You feel restricted when you are unable to do what you want to do
You feel supported when there are animals around you
You feel restricted when you have too many obligations

The above piece of text is an extract from a performative writing experiment co-written with the participants of a workshop that I and my colleague, artist-researcher Kristina Junttila¹ facilitated in a day centre for people with intellectual disabilities in Northern Norway in 2018. The workshop was part of a collaboration that resulted in the artistic outcome of my doctoral research: a performance installation presented at the international performance art festival New Performance Turku in Finland in 2018² (see figures 3 and 4; detailed description on pp. 79–81). Building on our professional experiences and research interests, the aim of our collaboration was to destabilise disability/abledness as fixed identity categories and to reflect on dis/ability as a theme that concerns everyone, informing how we experience and understand people's diverse, relational, and vulnerable agencies.

Theatre Academy of the University of the Arts Helsinki, the institution where I am based, conducts predominantly artistic research (e.g., Borgdorff, 2012; Hannula et al., 2014; Varto, 2018), which means that research involves artistic methods, often resulting in artistic outcomes. The artistic outcomes are formally examined as key products of the research. The written doctoral thesis, known as the 'commentary', can take diverse, sometimes experimental and 'expositional' (see Schwab & Borgdorff, 2014), forms to describe, comment on and/or complement the artistic outcomes. This article will be part of the commentary of my artistic doctorate.

1 <http://kristinajunttila.com/>

2 www.newperformance.fi/en/archive/2018

The ethical dilemma I want to address in this chapter concerns the paradoxical nature of vulnerability. I discuss the way vulnerability can on one hand be understood as a universal condition that we all share, and on the other hand is situated in specific circumstances and conditions, which highlights inequalities between individuals and social groups (Gilson, 2014). I reflect on how the different vulnerable agencies have been negotiated in my research project and aim to articulate the ethical insights that this negotiation brings forth.

After describing and contextualising my research process and its methodological influences, I introduce theoretical discussions on care ethics, vulnerability and dis/ability. Then, I describe the process that led to the artistic outcome and reflect on my choices concerning participants' agency. Finally, I conclude by discussing ethical insights that arose from the project.

A brief mapping of the research journey

I started my doctoral studies at The Performing Arts Research Centre, Theatre Academy of the University of the Arts Helsinki in 2015. Previously, I had worked in diverse contexts and settings in Finland and the UK in the boundary areas between the arts, health, and social care. At the start of my doctoral research project, I had been facilitating weekly creative movement sessions for three years at a day centre belonging to a Finnish private organisation in Helsinki that provides care services and activities for people with intellectual and developmental disabilities. This work was my practical starting point and the site of 'fieldwork' in the first stage of my research.

Between 2016 and 2021, I was also involved in the ArtsEqual research initiative.³ ArtsEqual was a large-scale research project coordinated by Uniarts Helsinki and funded by the Strategic Research Council of the Academy of Finland. The project examined how art as a public service can advance equality and well-being in society. According to ArtsEqual's final report, people who do not match the ableist ideal are often excluded from the arts and arts education services. ArtsEqual reinforced the rights of marginalised groups, including people with disabilities, and their opportunities to participate in artistic activities and arts education (Ilmola-Sheppard et al., 2021). Together with other ArtsEqual researchers, my aim has been

3 www.artsequal.fi

to develop a more nuanced and inclusive understanding of the power relations that impact people's possibilities of attaining artistic agency in different settings and life situations (Laukkanen et al., 2021).

Alongside my pedagogic work and collaborative research in ArtsEqual, I worked towards the artistic outcome of my doctoral research. I wanted to fully utilise the means of art in exploring ethical questions of dis/abled agency, whilst also making these questions visible in the contexts of art and artistic research. In summer 2017, I started a collaboration with artist-researcher Kristina Junttila. We set up a two-day workshop installation at the Research Pavilion during the Venice Biennale⁴, openly inviting people with professional and/or personal interests in dis/ability (Jaakonaho & Junttila, 2019). In 2018, we developed our piece *Post-Sense Room* for the New Performance Turku festival and asked scenographer and costume designer Ingvil Fossheim⁵ to join the collaboration. Her role was to help us in planning and implementing the visual and material elements of our piece. In the process of developing our piece, we organised a one-day workshop in a day centre of disability services in Northern Norway to develop and experiment with ideas and materials and to reflect on our questions together with people who have personal, lived experiences of disability. The final piece at the festival was open to the audience for three days. In the same space, I also presented my video installation entitled *Pako/Escape* based on data from the earlier stages of my research.

Mapping (and treading paths on) the methodological field

In the initial stages of my research, I had a sense that my work as a dance pedagogue at the day centre for people with intellectual and developmental disabilities would be a fruitful starting point for research. As I had been working in this context for three years, I developed my relationship and practice with participants to the point of becoming curious about starting to articulate and explore the tacit knowledge of the pedagogical practice through artistic research.

In the beginning of our weekly sessions, we always sat in a circle, discussing how everyone was, and how the week had been. Then we moved

4 <https://sites.uniarts.fi/web/research-pavilion-2017>

5 <https://www.ingvillfossheim.no/>

together. The movement was usually initiated by me first, suggesting something simple – such as stretching and rhythmic steps. Soon after this, the participants initiated their own movements – sometimes spontaneously, sometimes after I invited them to do so – which I mirrored with my movements and encouraged vocally. The participants responded in their diverse and unique ways, some more enthusiastically and vocally, some in more quiet and subtle ways. At the end of each session, we sat down again for a moment to reflect on our experiences. When I started the research project, the participants had all been coming to the group for at least one year, and they were all able to verbalise that they understood that I was going to document and reflect on our sessions for the purposes of my research.

After undergoing the formal process of getting a research permit and informed consent (see the ethical statement at the end of the chapter) from all the participants, I had to consider many practical questions: How should I approach documentation? How will I write about my experiences? How can I get information about the participants' experiences? As I was interested in the ethical questions concerning agency, every methodological choice felt meaningful. I needed to reflect on and explore different options before making every choice, as the choices often directly or indirectly concerned the agency and self-determination of the participants. I started taking notes and experimenting with documentation. I also became interested in the materiality of the space in which I ran the group: the fascinating combination of clinical whiteness, technological devices, brightly coloured soft materials, and handmade objects (see Jaakonaho, 2024). I photographed the environment to capture interesting details (see figures 1 and 2).

In my methodological choices, I found the intersections between artistic, qualitative, and ethnographic research practices particularly inspiring. Artistic research is a methodological paradigm in which knowledge emerges from and is articulated through artistic, embodied, experimental, and performative practices, usually conducted by artists and arts educators (Borgdorff, 2012; Hannula et al., 2014; Varto, 2018). I see artistic research not as a clearly defined, static framework but as something that is being constantly developed and redefined through different approaches and artistic practices, often in relation to other research traditions (e.g. Borgdorff, 2012). As an arts pedagogue and interdisciplinary practitioner working in the boundary areas between arts, education, and social care, I am interested in a broad and inclusive conception of art that acknowledges that art has diverse meanings and purposes in different contexts. As Borgdorff



Figures 1 and 2. From the day centre of disability services where I worked during the first stage of my research. Photographs by L. Jaakonaho.

(2012) points out, it is characteristic of art to escape essentialist definitions, meaning that the boundaries between the art world and other domains of life are subject to constant debate.

Ben Spatz (2015) advocates a 'research culture' in performing arts and other embodied practices that emphasises continuous creation and transmission of knowledge rather than individual ability. Building on Foucault's writings on technique, knowledge and power, Spatz argues that embodied practices are structured by knowledge in the form of technique, and therefore "technique is knowledge that structures practice" (Spatz, 2015, p. 1). Spatz (2015) divides the singular notion of 'art' into plural 'arts' defined as fields of craft, technique and knowledge characterised by embodied encounters of bodies rather than audiences' encounters with representations and spectacles in the public sphere. For me, this conception of art is interesting in the context of artistic research, particularly in relation to the agency of the researcher. As an artist-researcher I produce knowledge through embodied and ephemeral encounters in pedagogic and participatory situations; I articulate, make visible and build on the tacit knowledge that is embedded in the techniques of moving, interacting, and being.

My other field of methodological inspiration, *post-qualitative research* rejects conventional, predetermined research methods and practices. Ontologically, it is inspired by the Deleuzian philosophy of immanence that places life, thought, being and nature on a single surface of existence (St. Pierre, 2021). Both artistic research and post-qualitative inquiry have emerged from a friction with established qualitative methods (Østern et al., 2023). The two methodological fields share a postpositivist understanding of knowledge as relational, porous and indeterminate, supporting creative, polyphonic inquiry that combines different voices, social domains and discourses. However, according to David Rousell (2019), the relationship between art and post-qualitative inquiry is ambivalent. Rousell develops Deleuze and Guattari's (1994) argument that art, philosophy and science operate on 'different planes of material-semiotic production', suggesting that if art is treated as the solution to the post-qualitative methodological 'crisis', then the knowledge-producing potential of art may be diminished to serve the purposes of theory. Rousell (2019) proposes that art should be taken up as vigorously as any theoretical part of research, without reducing one element of the research assemblage to another. My choice to work in the direction of participatory artwork at a performance festival, was inspired by a similar logic: I wanted to take the artistry of the research seriously and present it in a context in which it would be viewed as artwork.

At the beginning of my research, during my interactions with the participants of the groups that I was facilitating, I was fully immersed and engaged in the embodied situations and encounters that I was studying. As a researcher, it was clear that I could neither be a neutral observer nor an equal member of the group. Consequently, I started thinking about the pedagogic situation, as well as my methodological experiments, as *performative*. Performative research started with Brad Haseman's 'A Manifesto for Performative Research' in 2006 and was further developed in artistic research and the social sciences (Arlander, 2018; Bolt, 2008, 2016; Haseman, 2010; Østern et al., 2023). In performative research the researcher is entangled with the researched phenomena through her embodied, sensuous being and by means of a performative approach towards languaging; "(...) not only using existing concepts and modes of creation, but actively languaging research phenomena in new ways." (Østern et al., 2023, p. 2). The research process emerges through constant negotiations and entanglements across the material, social and discursive planes. Knowledge is seen as a fluid and complex process of creation, involving also more-than-human agents (Østern et al., 2023). This resonates with the ways in which I was entangled with embodied encounters and material elements in my research, whilst experimenting with ways of languaging the situations of inquiry.

In my research, ethical questions were pivotal, and methodological considerations were always closely tied to questions of agency and power. This position resonates with the discourses of *feminist ethnography*. According to Beverly Skeggs (2007), feminist ethnography is a plural term, as are both words separately: 'feminism' and 'ethnography'. Feminist ethnographers adopt a reflexive approach to problematising the objectification of the Other.

My aim was to develop alternative ways of acquiring and articulating knowledge through bodily encounters, material negotiations and affective utterances. This kind of knowledge production can be seen as a *decolonial* project. Spatz (2019) makes an important distinction between decolonisation and decoloniality: decolonisation is, and should be, about the transfer of political power and sovereignty from a colonising society to an indigenous one, whereas decoloniality refers to a more thorough and complex transformation of knowledge. Emerging modes of artistic research, practice research and embodied research are grappling with decoloniality at a methodological level (Spatz, 2019). This distinction resonates with my experience of grappling with questions that are close to the discourse of decolonization, whilst being aware that I am a White, abled and

privileged researcher who has not experienced personal struggles caused by possessing a racialised or disabled identity. I would not say that my research is decolonizing – however, the notion of decoloniality, as Spatz (2019) describes it, supports the way I see that on a methodological level my research contributes to a broader transformation in institutions of academia, aiming to challenge legacies of colonialism.

On agency, care and vulnerability

My understanding of agency is in essence informed by a sociological definition, which sees individual agency and social structures as reciprocally constituting; individual agency is shaped by social structures, whilst social structures are also shaped by individuals and their actions (e.g. Giddens, 1984). Drawing from contemporary feminist and new materialist theories (e.g. Barad, 2003; Butler, 2016; Gamble et al., 2019), I take this idea of reciprocity further by acknowledging the relationality and interdependency between different agents, and between individual human agents and the non-human agency of the socio-material environments in which they act (see Jaakonaho, 2024).

In addition to my methodological experiments and artistic-pedagogic explorations, I have aimed to facilitate reciprocal and affirmative embodied interactions with dis/abled participants. In this practice, I have been informed by practices and questions of *care*, and found inspiration in *care ethics*. Care ethics is a feminist philosophical approach to moral theory that sees ethical concerns as relational, situated and embodied. Building on the works of Carol Gilligan, Joan Tronto and other key scholars of care ethics, Selma Sevenhuijsen (1998, p. 56) proposes a shift from the search for rules, principles, and duties to situated questions concerning responsibility, such as ‘How can I best deal with vulnerability, suffering and dependency?’

Erinn Gilson (2014) has further developed the feminist ethical standpoint on the basis of a multifaceted and critical reflection on the notion of *vulnerability*. Drawing on Butler, Deleuze, Cixous, Merleau-Ponty and other influential thinkers who touch on questions of vulnerability, she develops an *ethics of vulnerability*. As Gilson points out, how we perceive and understand vulnerability is ethically significant. If we consider vulnerability to be something inherently negative or a weakness, denying our own vulnerability and valuing invulnerability, we fail to respond ethically to others’ vulnerabilities. This can have stigmatising and controlling effects, making

the whole concept of vulnerability problematic. Instead, if we acknowledge vulnerability as an ‘ontological condition’ and a complex, ambiguous and multifaceted ‘condition of potential’ that can also have positive effects, such as connection, transformation, empathy, and compassion, we can accept vulnerabilities in ourselves and others and face them with ethical awareness and sensitivity (Gilson, 2014, pp. 10–11). However, we should still remember that although at one level vulnerability is a universal condition that we all share, there are also ‘situational vulnerabilities’ that are determined by people’s social positions and circumstances (Gilson, 2014, p. 37).

These views on ethics and vulnerability resonate with the ways in which I approached ethical questions and situations of embodied vulnerability in my research. I was more interested in searching for ways of making ethical questions visible and embodied and articulating them through artistic means than in finding answers or moral rules. I reflected on vulnerability as a shared and situated experience – something that concerned not only the disabled participants but was also embodied in me, although in a different way.

On dis/abled agencies

During my work of facilitating the movement groups in the disability services context, I became interested in how experiences of dis/ability are mediated by society and social-care institutions. I aimed to shift the focus from a marginalised group of others to asking how questions of dis/ability concern everyone, as we are all vulnerable and most of us struggle with society’s ableist structures and practices at some point in our lives.

Authors in critical disability studies have challenged the binary logic of disability versus ability, investigating how disability is produced and conditioned through socio-political structures and historically constructed ideologies that also affect non-disabled people (see, e.g., Davis, 2016). Dan Goodley (2018) makes a useful distinction between disablism (the direct discrimination of people with disabilities) and ableism (societal structures and practices that favour non-disabled people), claiming that disablism and ableism can only be understood in relation to each other. In other words, the normative category of ability concerns everyone in contemporary society. As citizens, we are expected to be self-sufficient, autonomous and independent. If we fail, we may be rendered disabled.

Using the notion of ‘compulsory able-bodiedness’, Robert McRuer (2002) shows that the norms attached to able-bodiedness are intrinsically

impossible to fully achieve and that, in fact, everyone is only ‘temporarily able-bodied’ – that is, everyone will eventually experience disability if they live long enough. This line of thought shifts the focus from disability to the patterns and effects of *ableism*. According to Bradley Lewis (2013, p. 129), ableism refers to the ‘social stigma and oppression against the physically different’. Fiona Kumari Campbell (2009, p. 44) defines ableism as ‘a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical, and therefore essential and fully human)’.

In my encounters with disabled participants, it was evident that they had many more meaningful things in their lives than their disabilities. One person was a mother and grandmother and enjoyed talking about that part of her life. Another person sometimes dressed up in women’s clothes and sometimes in men’s and enjoyed taking part in disability community events. There was also diversity in how much support the individuals needed – some were very independent, whilst others needed more support and assistance. This diversity resonates with an *intersectional* understanding of individuals’ social positioning, which acknowledges the complex and multiple dimensions of intersecting identity categories and their effects on individuals’ social positions, opportunities, and experiences (Crenshaw, 1991).

Whilst learning about dis/ability, I also became aware of the common, problematic assumption that disabled people suffer from their disabilities. Contrary to this assumption, I often witnessed a sense of joy and affirmation that the participants brought to the space, and I was uplifted by the many positive stories and experiences that they shared during our encounters. These observations resonate with the *affirmative model* of disability, which is connected to the development of the Disability Arts Movement (Swain & French, 2000). As John Swain and Sally French (2000) describe, the affirmative model challenges the value-laden presumption that disability always entails personal tragedy, repudiating the dominant value of normality, promoting positive identities and experiences, and celebrating people’s differences.

Supported and restricted agencies

The process that led to the performative outcome of my research developed from my observations and methodological experiments in the pedagogic practice, as discussed earlier, and from my collaboration with

artist-researcher Kristina Junttila. Informed by our embodied experiences of working with dis/abled people, Kristina and I chose the theme of *support and restriction* as a starting point that we thought many people could relate to, regardless of their abilities or disabilities. We believed that everyone has experiences of being supported and restricted by the environment, and the theme functioned as a means of approaching questions of dis/ability without focusing on a specific group of others. This thinking was based on our understanding that dis/ability experiences are mediated by ableist structures and practices (see, e.g., Campbell, 2009; Goodley, 2014, 2018).

Whilst developing the piece, Kristina and I wanted to involve people who had personal knowledge and understanding of disability as experts who knew more about disabled experiences than we did. A few weeks before the festival, we organised a workshop in a day centre of disability services in Northern Norway. To address our ethical concerns, we considered what the experience was going to be like for the participants and tried to be as transparent, clear and as fair as possible. It is important to acknowledge that our strategies were not 'neutral' in relation to the problem of colonising practices in participatory research (see Seppälä et al., 2021; Tuhiwai Smith, 2021). As researchers, artists, and educators, we must be particularly aware of our privileged positions in such cultural contexts as Northern Norway, where, similarly to other Nordic countries, the indigenous Sami people have been subjected to abuses, violations, and racism by the settler governments.

The aim of the workshop in the day centre was to try out some embodied experiments related to the theme of support and restriction, along with collective performative writing, to produce material for our performance installation. Before the workshop, we contacted the staff of the day centre to discuss the details of our visit. We also visited the site the day before the workshop and spent time getting to know the people and the environment, taking part in their daily activities, and expressing our interest in and wish for mutual dialogue. In the workshop, we used our professional skills and knowledge to create a reciprocal situation in which the participants were involved as active agents. We explained, in an accessible and appropriate way, what we were there for (to produce material and gain insights for our artwork) and made sure that we had everyone's informed consent and that the participants understood that they had a right to withdraw at any point if they chose to do so. The participants responded positively and were willing to take part in what we offered.

In the workshop, we conducted a writing experiment in which we gave the participants pages of sentences that we had started and asked them to finish these sentences in their own words, expressing their experiences of being supported and restricted (see the extract at the beginning of this article). We also facilitated some physical exercises with music and material elements (cloths and stretchy ropes), aiming to create a holistically engaging and playful atmosphere, whilst exploring the theme of support and restriction in an embodied way. Afterwards, we gathered all the texts that were produced in the workshop into one document, which we also sent to the participants. We translated, edited and recorded the text and presented it as one of the five audio tapes that audiences were invited to listen to as part of the final piece in Turku.

Post-Sense Room and Pako/Escape: Welcoming different agencies into a performative space

The following description depicts *Post-Sense Room* and *Pako/Escape*; the collaborative artistic outcome of my research, presented at the New Performance Turku Festival in September 2018.

As you enter the space, the first thing you notice is a clothing rack with different colourful and modified pieces of clothing, some with objects, such as balloons and sandbags sewn inside the fabric. On the floor next to the clothing rack, there is a note: 'Please choose a piece of clothing. Wear it whilst you are in the space. When you leave, please put the piece of clothing back.' One of the artists is sitting on a bench, crocheting a thick rope out of colourful strips of Lycra fabric. The rope travels through the space, around hammock chairs, large beanbags and three TV screens with pillows in front of them on the floor. Another artist is performing simple repetitive exercises. Next to her, she has diagrams showing instructions for movements and a bowl of pens, which she uses to trace her movements on the floor every now and then. The hammock chairs and beanbags have MP3 players and headphones attached to them. As you sit down on a beanbag and put on the headphones, you hear a voice asking you to pay attention to different body parts, pointing out that you may or may not have these body parts, and you can always choose another one. When you sit on a hammock chair, you hear a text that at first sounds like a list of facts about the body, but some sentences are fictive, such as 'we have brain cells in the soles of our feet'. When you sit on another hammock chair, you hear a list of different things that can support and restrict people. The voices in all these recordings are slightly altered and carry metallic echoes or glitches. One audio



Figures 3 and 4. from *Post-Sense Room*, a performance installation at the New Performance Turku festival in September 2018. Photographs by Jussi Virkkumaa (Image 3) and Julius Töyrylä (Image 4).

option includes only music with mellow and rhythmic ambience. Sitting on the bean bag in the back corner, you hear excerpts from theoretical texts about disability and agency, read by computer voices with different dialects of English. On one of three TV screens, you see the artist with a fur coat sitting on a rocking chair, and then tidying up a room in a care facility. A muffled voice on the soundtrack of this video talks about the

event of a disabled participant going missing after a movement group, and later being found in another part of the city. Another video shows a room full of people dancing, with all their faces pixelated. One video depicts landscapes – mountains, lakes, dwarf birches – filmed from a car window, followed by close-ups and still images of colourful soft materials, furniture, assistive technology, everyday items, and decorative objects in a care facility.

The concept for *Post-Sense Room* came from our interest in *sensory rooms* (also known as multi-sensory rooms), spaces in care homes and educational institutions meant for sensory stimulation and relaxation for neurodivergent people (e.g. Fowler, 2008). We wanted to develop a space that functioned as *a space of care*, both for ourselves and the audience, whilst also problematising questions of dis/ability and agency. The space, with its material elements, verbal instructions, and thematic contents, was designed to engage everyone that entered the room to reflect on their vulnerable and diverse agencies by engaging with materials that slightly changed (by supporting and restricting) their embodied experiences, such as clothes, hammock chairs and bean bags. The performative texts that were presented as audio tapes also suggested different perspectives on embodied agency. My performative action was crocheting; an activity that I found meditative and grounding whilst creating a visual element that connected the different parts of the space. The action that Kristina chose to do was to repeat physical exercises and trace the movements on the floor. The exercises were individually selected and given to her by a physiotherapist. Audience members were also welcome to try out our actions if they wanted to. My role also involved acting as a kind of ‘gallery guard’ by answering audience members’ questions or offering assistance if someone asked for it. The performance installation was open to the public for three days.

The three videos displayed in the space had their own title in the festival programme, *Pako/Escape*, and were produced by me alone. In the videos, I used documentation from various stages of my research. Filming transitions and material details between and within the different contexts of my research, including footage from the journey from Helsinki to Northern Norway, was a way of highlighting the fact that relations, transitions, and material elements were significant in the research process.

The audio in one of the videos was a text about the participant going missing, and later being found in another part of the city. This was a true story from the initial stages of my research. After one of the movement sessions I facilitated, one participant went on a walk on her own, rather

than taking the taxi to the supported housing that was waiting for her at the day centre. Afterwards, we reflected on this incident together with the staff of the day centre, to clarify roles and responsibilities. As I was not formally a member of staff at the day centre (I received arts funding to facilitate the sessions and therefore did not have a formal work contract), my duties did not include assisting participants in their everyday activities outside our sessions. Also, I did not have adequate access to information about the participants to always be aware of what kind of support they needed. However, I felt responsible and concerned when I heard that the participant had gone wandering around on their own. I included this incident in the video installation because I saw it as ethically significant. The incident brings forth interesting questions of responsibility, institutionalisation and agency: How much agency and free choice does a disabled person have in their daily life? How much can their freedom be restricted, by whom, and on what grounds? How is their agency mediated and controlled by the institutions that provide support?

The choices I made in anonymising and framing the videos were ways of addressing the problematic questions to do with the objectification of vulnerable people in research. Rather than aiming to resolve or hide the problematic relationship between my agency and the agency of the participants, I wanted to make these problematics tangible in the artwork. I saw the choices of anonymising and framing as both aesthetic and ethical: for example, pixelating people's faces is a way of ensuring that I comply with formal research ethics, but it is also an aesthetic choice.

There were many practical questions that we needed to address when developing *Post-Sense Room*, including questions of accessibility: Who was invited into the space? Whom was it for? Who heard and knew about the space? What kind of agency did the audience and the participants have in the piece? We wanted to ensure that the space was as accessible as possible – that the audience could choose how long they wanted to stay and how they wanted to engage with the objects and elements of the space. All audio with language had both Finnish and English options, and there was also a non-verbal option (the music). We were also prepared to physically adjust the space according to the needs of visitors, moving things around if needed.

We were happy that our piece was attended and enriched by a diverse audience, including families with young children and people of different cultural, professional, and personal backgrounds. At the end, we held an open discussion in the space to conclude the experience and reflect on

it together with audience members, supervisors, and examiners of my research. Although it was obvious that the people who took part in this discussion were either already familiar with my research or otherwise interested in the work, in the recording of this discussion it is evident that the piece facilitated some meaningful and affective moments and reflections.

On the paradoxes of vulnerability and participation

During the research project, I consciously chose to distance myself from the original context of my research (the day centre) and translate my questions into an artistic collaboration in another context (the performance festival). I am aware that the question of participant involvement in relation to the final products of my research is ethically significant, and one in which the paradoxical nature of situated and shared vulnerability (Gilson, 2014) is tangible. When I reflect on my choices now, I think it may have also been possible to carry out the artistic outcome of my research in closer collaboration with the disabled participants of the research. However, at the time I felt that inviting the participants to think about the complex questions of artistic research with me did not seem feasible, and offering them limited agency – for example to physically perform roles that I had given – did not seem ethically justified either. In the end, my doctoral research project was going to be in my name. The asymmetry of the relationship – the paradox – could not be easily resolved, and participation was not a simple answer for me.

The ethical insight that I gained from reflecting on these choices pertains to the possibilities and limits of participation. Whilst it is important and meaningful to offer arts activities in social care contexts and include disabled participants in artistic research, all the while remaining open, vulnerable, and ethically sensitive when facilitating such activities, we should problematise artistic and academic practices that exclude people with disabilities or only offer them marginalised, limited roles and agencies. We should also problematise participatory projects, in which disabled people's agency is determined and mediated by abled people. The complexity of the possibilities and limitations of participation is something that we should continue to reflect on, rather than trying to find quick fixes or ostensibly ethical solutions.

In the process that led to the artistic outcome, my agency as a researcher was formed in ethically charged negotiations with the agency of the participants, collaborators, and audience members. I aimed to create inclusive situations and ways of thinking, taking into account diverse and vulnerable others and welcoming them to interact within the elements of the research assemblage. The questions concerning the participants' vulnerable agencies touched on complex debates on care, disability, and ableism. Frictions between different contexts became tangible in light of the complexity of the social-material-discursive phenomenon of dis/ability.

In line with Rousell's (2019) problematisation of the relationship between art and post-qualitative research, I would like to think that the way in which the artistic outcome tackled the questions of my research cannot be reduced to a theoretical reflection. The multiplicity of voices, experiences, choices, and encounters created an assemblage in which the meanings and knowledge were moving and emerging beyond anything that can be theoretically framed or pinpointed.

Throughout the research process, including the process of writing this article, I aimed to integrate and develop a theoretical discussion that would both support and problematise my choices. I brought practical insights into dialogue with theoretical discussions to produce knowledge that hopefully contributes towards a more nuanced and ethically sensitive understanding of diverse and vulnerable agencies in the boundary between arts, research, and social care. I am not going to claim that, in my research, I managed to completely avoid colonising and ableist patterns, despite my efforts to address ethical concerns throughout the process. I followed through a learning process in which I was constantly becoming more aware of problematic patterns, trying to articulate and challenge them and re-think my own practices. By discussing and problematising my methodological, artistic, and pedagogic choices, my aim was to shed light on complexities and ethical tensions related to the potential of art and artistic research in the context of dis/ability and care.

Statement on formal research ethics

The research project presented in this article has received an ethical statement from The Ethics Committee of the Helsinki and Uusimaa Hospital District. All the disabled participants of the research, or their legal trustees,

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