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# Negotiating boundaries: reflections on the ethics of arts-based and artistic research in care contexts

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## ABSTRACT

**Background:** Arts-based practice and research in care has increased significantly. There is a need to examine the ethical issues arising from this complex phenomenon, conceptualised as boundary work.

**Method:** To support interdisciplinary understanding in artistic and arts-based work, we collaboratively explored three arts-based research projects implemented in diverse care and healthcare contexts. The ethical issues related to boundary work were negotiated through reciprocal, in-depth reflection.

**Results:** Arts-based and artistic research allows embodied, sensitive, and sensible encounters to emerge, in which the boundaries between artistic agency, professional positions, and even notions of evidence may be challenged. The notion of vulnerability emerges as a central ethical feature of boundary work.

**Conclusions:** Articulating ethical concerns in artistic-pedagogic boundary work and research can promote a more nuanced understanding of power relations in cross-sectoral practices. It may help develop services that support the agency and holistic well-being of individuals and communities.

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## Introduction

In recent decades, arts-based practice and research in care contexts has increased significantly. This has created a need to examine the challenges of this kind of occupational activity, conceptualised as *boundary work*, in which professional and disciplinary boundaries are negotiated, crossed, and spanned (Daykin, 2019, 2020). In particular, a more detailed exploration of the ethical challenges of arts-based and artistic research in health and social care is needed. In this paper, we articulate the specific ethical concerns that we have encountered when engaging in the boundary work of arts and health practice. We, the four authors of this paper, became associated through our involvement in the Finnish research initiative ArtsEqual, and our research is rooted in the fields of arts-based, artistic, and cultural studies in Finland. In this article, we discuss three separate arts-based and health research projects implemented in different care

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contexts in the Helsinki metropolitan area: 1) a children's hospital and an eldercare hospital, 2) a day centre of disability services, and 3) a psychiatric hospital. The context and methodologies used in each of these projects raise distinct ethical issues. However, we were able to identify common ethical concerns in arts-based and artistic research in healthcare and care environments.

This paper is organised as follows: First, the ArtsEqual project as a grounding research initiative in relation to our boundary work is introduced, and key ethical concerns in arts and health practice are identified. Second, the research projects and their contexts are presented, along with reflections on specific ethical concerns arising from these particular projects. Subsequently, deeper reflections are represented through exploring the procedures of each research context, which simultaneously regulate the relationships between researchers and participants, and provoke a discussion of fundamental ethical issues related to vulnerability. Finally, some novel perspectives of cultural well-being and boundary work more generally, gained from articulating the ethical concerns of arts-based and artistic research in diverse care contexts, is taken into consideration.

### **Theorising boundary work in the ArtsEqual research initiative**

Our research is part of ArtsEqual, a six-year (2015–2021) interdisciplinary research initiative. This article contributes to the research projects' main objective of developing arts practice and art education as a form of public service in support of social justice and improvements in well-being and the social determinants of health. This objective requires cooperation between disciplines and professions. As Daykin (2019, 2020) suggests, examining the field of arts and health in terms of boundary work is useful because it reveals important mechanisms outlining the potential of the arts to connect diverse fields and groups (Daykin, 2019, p. 11).

Our work has contributed to the subgroup of Arts in Health, Welfare, and Care, which investigates accessibility to arts-based services in care contexts. Cultural rights – in other words, the “right to participate in the arts, to develop oneself and one's community through the arts and to express oneself freely” (Lehikoinen, 2019, p. 100) – are based on the UN Declaration of Human Rights and are entrenched in the Constitution of Finland. Namely, enabling access to and participation in arts and culture services for people who are temporarily or permanently institutionalised in care facilities is an equity issue and a constitutional right. Our research subgroup, consisting of approximately 10 researchers, argues that participation in arts and culture increases individuals' cultural and social capital, improving their capability to make choices that foster well-being and contribute to the common good (Lehikoinen, 2019).

Cultural well-being is a relatively new concept addressed in reference to the arts, health, and well-being in Finland. Cultural well-being is defined as a phenomenon in which people experience culture and the arts as increasing their well-being and as a field of multidisciplinary and multi-professional activity, development, education, and research, as well as a field of service (Lilja-Viherlampi & Rosenlöf, 2019). As such, the field of cultural well-being is a useful example of a boundary zone where various disciplines, discourses, and practices intermingle in boundary work. In relation to cultural well-being, cultural capital refers to skills, habits, and education gained through socialisation, while social capital is associated with actual and potential social networks (Bourdieu,

1986). According to Nussbaum's (2011) capability approach to well-being, every individual has the capability to live a rich life. Within this framework, Bourdieu's and Nussbaum's theories inform the concept of cultural well-being. As boundary work, we see cultural wellbeing as a site for ethical negotiations across practical, organisational, and policy levels (see Lehtikoinen, 2019).

As the first multi-year arts-based research project supported by the Strategic Research Council of the Academy of Finland, ArtsEqual is unique. Along with prestige, research council funding creates expectations of accountability. As ArtsEqual researchers and project facilitators, and through our own individual careers, we have witnessed the potential of art and art education to enhance well-being and support social justice. We also have acknowledged how the underlying epistemologies of different disciplines shape choices related to *why*, within theories and methodologies; and *how*, within procedures and practices, research is conducted and assessed.

### Reflexive and ethical research approach

Among other forms of boundary work, arts research in care contexts stretches and spans reflexively disciplinary boundaries and requires critical, in-depth epistemological examination. To support an interprofessional understanding and interdisciplinary collaboration in artistic and arts-based work and projects, our aim is to reflect on the ethical issues emerging from this complex, ambiguous, and interlayered quality of boundary zones (see Akkerman & Bakker, 2011).

This article is a collaborative exploration, facilitated by the main author, inspired by Daykin's proposition (Daykin, 2019) that arts and health practice can be understood as a form of boundary work. We began our explorative journey with each researcher independently reflecting on their doctoral arts and health research project. We then shared our reflections with the group during reciprocal discussions and identified ethical similarities and differences between the projects. The collaborative exploration and identification of shared concepts, meanings, and language proved to be surprisingly challenging, although we all had similar research aims and had already worked in the same research group. The contradicting reflections and collaborative challenges consisted of for example, our diversified understanding on what kind of processes and conceptualisations artistic research, researcher's integrity, or procedural and practical ethics, included.

Arts, health, and well-being activities and research in care contexts require attention to both procedural ethics and ethics concerning artistic and research practices (Cox & Boydell, 2015). By procedural ethics, we mean protocols and procedures that aim to ensure, for example, the self-determination, anonymity, confidentiality, and safety of research participants. Procedural ethics are an inextricable part of, for instance, institutions' research approvals. All research presented in this article has received ethical approval and research permits and is in full compliance related to the institutional and national legislation, as well as codes of ethics (see Ethical considerations; Finnish National Board on Research Integrity (TENK), 2019). Beyond procedural ethics, this article is grounded in a critical reflection on immediate, embodied, and relational experiences in artistic and arts-based research in care contexts. We examine the ethical features of encounters generated by artistic and pedagogic means between participants, researchers,

healthcare staff, and audiences. These encounters are related to and sometimes *reorganise* normative social structures and values. In our work, each of us had a somewhat different understanding of how these normative ethical dimensions overlap and were intertwined depending on the specific context and setting of the respective project. This resulted in a rich dialectic of conflicting and overlapping reflections on how to overcome numerous ethical challenges when the concept of (cultural) well-being served as a theoretical lens to understand work within boundary zones.

### **The research projects: music, movement, and vocal exploration**

The three projects use different art mediums and take place in diverse healthcare contexts: 1) music interventions in a neonatal intensive care unit (NICU) of a children's hospital and in somatic wards of an eldercare hospital; 2) creative movement in a day centre for people with disabilities; and 3) non-verbal vocal exploration in a psychiatric hospital.

#### ***Healthcare musicians' interprofessional work in hospitals***

Taru Koivisto is a music therapist, music educator, and health promotion professional. Her research project explored healthcare musicians' work in a children's hospital and an eldercare hospital, and the data collection of the research project was conducted in strictly regulated medical environments: an NICU, infection wards, and orthopaedic wards. Within the project, she investigated healthcare musicians' professional work and shared music-making practices in these medically oriented hospital ward communities. The project considered the boundary work not only of healthcare musicians but also of the researcher herself as she navigated and clarified the professional competencies, institutional support, and higher music education needs of this interprofessional field. Negotiation and navigation between disciplines, organisations, and their various ethical policies and practices was required throughout the research process. During the data generation, Koivisto observed healthcare musicians' work in the hospital communities. She also conducted semi-structured one-on-one interviews with healthcare musicians and members of the respective hospital communities. In addition, the research project included a systematic review of healthcare musicians' work and professional practices in the field, as well as supplementary interprofessional interviews (for example, with administrators of collaborating cultural organisations) and interviews with healthcare musicians working in other institutions. This multi-method collection of empirical data and the two research settings helped to construct a comprehensive picture of music work in healthcare, where the ethical responsibilities of healthcare musicians are inextricably intertwined with their music practices, namely *hybrid* (Gielen, 2009) and *expanding* (Westerlund & Gaunt, 2021) music professionalism.

#### ***From dance/movement in disability services to collaborative artistic research***

Liisa Jaakonaho's research is situated in boundary zones where the arts, social care, and academic research intersect. Her research interests are rooted in her multidisciplinary background as a dance pedagogue, dance movement therapist, and performance artist

working in the arts and health/social care. She investigates the ethical concerns that she has encountered when facilitating creative movement groups in a day centre for adults with cognitive and developmental disabilities, exploring how she can articulate these concerns and make them visible by artistic means and what kinds of interactions and relationships between different contexts, settings, and agencies emerge in this research.

In the first stage of her investigation, Jaakonaho recorded her own and her participants' embodied experiences of creative movement using video documentation of eight group sessions; a multimodal group interview (i.e. an interview including writing and movement; Svendler Nielsen, 2009) with the group participants; and her own ethnographic writing, including notes after every session and performative writing (Pelias, 2014) experiments. In the second stage, she continued to explore how to make ethical concerns visible by artistic means, setting up a participatory performance installation and a video installation at an international performance art festival. In the video installation, Jaakonaho used data from the first stage of the research, including anonymised fragments of video documentation and voice recording transcripts. The performance installation was produced in equal collaboration with performance artist and researcher Kristina Junttila. The collaborative artistic process also included a workshop in a day centre for people with intellectual disabilities in Tromsø, Norway. In this workshop, Jaakonaho and Junttila facilitated creative movement and writing exercises on the theme of *support and restriction*. They chose this theme as an "embodied metaphor" for the relational ethics of disability and ability and as an accessible starting point for interactions with the participants. Text material produced in the workshop was voice-recorded and used as an element of the performance installation, addressing ethical concerns regarding participants' agency in the artistic process.

### ***Shared non-verbal vocalising in a psychiatric hospital***

Fast is currently finalising her artistic research (in preliminary examination phase) conducted in cooperation with the Finnish University Hospital of Psychiatry. Based on her previous work as a singer, performance artist, and pedagogue, Fast created in her research, a practice of mutual non-verbal vocal art. She used this vocal practice to explore how non-verbal affective interaction with adults using psychiatric care and mental healthcare services changes the experience of connection between the participants. In this vocal work, the participants activate and join their voices to create non-verbal resonance spaces together. This practice enables a transition from cognitively oriented verbal interaction to a more affective and embodied non-verbal vocal encountering. It can be especially useful for fostering social connections in situations in which verbal communication is not feasible. As a transdisciplinary enquiry involving artistic, philosophical, and medical (psychiatric) research methods, this project is another example of boundary work that bridges different epistemic paradigms, methodologies, and ethical priorities.

The research consisted of two vocal workshop periods with the participation of people with psychiatric disabilities. Fast recorded, composed, and published the shared anonymous voices in the sessions as a series of research artworks called Hospital Symphonies in close collaboration with several artistic professionals. These site- and situation-sensitive works were then shared in the psychiatric hospital space (2015), in a concert hall (2018), and on the radio (2019). Fast's vocal practice creates primarily sensate, implicit, and

embodied knowledge by focusing on the bodily sensing on how a vocal atmosphere feels like to participants and listeners (Fast, 2018; see also Varto, 2018). Fast investigated this sensate knowledge by interviewing participants and psychiatric professionals from the hospital, analysing psychiatric questionnaires completed by the participants, collecting anonymous feedback from listeners, and using autoethnographic methods to explore her own interpretations and position as an artist-researcher. Attuning to non-verbal interaction draws attention to the immediate relations with people experiencing suffering. According to Fast's findings, *the ethics of attunement* (Fast, *in press*; Fast, 2018; Leppänen & Fast, *in press*) become crucial for enabling vulnerable encounters between the participants, as well as the listeners. In Fast's work, the ethics of attunement has emerged immediately from within the sensorial and non-verbal research practice (from "the ethics of attunement" of listening to speech and silence, see Lipari, 2014)

### **Ethical concerns arising in social and healthcare research contexts**

In the presented research projects, social and healthcare contexts constituted a strictly regulated environment for arts-based and artistic research activity. The research approvals, participants' consent, and boundaries of professions guided the relationships between researchers, staff, and participants.

Procedural ethics in many institutions, especially in academic and medical contexts, aim to ensure that participants are aware of the research objectives and understand the consequences of their participation. All three researchers negotiated the statuses of their research and navigated between medical, artistic research, and social and behavioural sciences procedures. Koivisto's interest in exploring hybrid arts professionals' (Gielen, 2009; Noordegraaf, 2015) working environments and music practices created a need to cross the boundaries of research methodology and knowledge building in medical and artistic-pedagogic practices. Her research was based on sociological views of people as holistic beings whose agency, capability, and actions in life are co-constructed with other people. In the field of socially engaged music practices, music-making, or musicking (Small, 1987), was the sociocultural action of making every kind of music with and for people, as well as a way to engage in relationships with them to promote well-being (Koivisto, 2021; Odendaal et al., 2014). This view implied the democratisation of music-making and everybody's participation in the hospital environment.

Koivisto met challenges, for example, in combining the highly rigorous research processes regarding the patients determined by the hospital protocols and the more reflexive research methodology of the social sciences in an ethically relevant manner. The participants seemed to make assumptions about this research being implemented in a solely medical manner, including a plan to investigate the effectiveness of "controlled" music interventions in the wards. However, unlike music therapists or other registered healthcare professionals, music practitioners are not expected to be responsible or accountable for the health issues of the patients receiving care in the ward. The approach as a whole required a different framework, which Koivisto considered non-medical.

In Jaakonaho's experience, working in the complex field of disability required cooperation between different professionals and called for ethical sensitivity in providing for the unique needs and characteristics of each individual. By the start of her research project, Jaakonaho had held creative movement sessions in the day centre for three years, and all

participants in the documented sessions had been in the group for at least one year. As the pedagogic work shifted to a research project, formal and informal research procedures revealed ethical aspects of Jaakonaho's practice that she had not considered before. For example, she became more aware of her role in the organisation as a visitor and outsider rather than as a permanent staff member. In practice, this meant that she did not have access to full information about the participants, such as details of their diagnoses, which could have been useful in minimising the risks of miscommunication. On the other hand, a diagnosis can influence the way in which a person is seen, and a lack of such information can sometimes be a better starting point for dialogue. In this regard, the ethical procedures exposed an interesting ethical tension in the practice between the wish to avoid reinforcing stigma and the need to know enough to ensure safety. As artistic and arts-based researchers, Fast and Koivisto faced similar ethical challenges in their research contexts.

Even if consent for participation in an arts and health project is provided and documented at the beginning of the project, it is often necessary to negotiate and reassess it later. In Fast's research with people in need of psychiatric help, the participants consented (among other aspects of the research) to be part of a vocal artwork, in which their anonymity was ensured by artistic methods, such as sound editing. Nevertheless, while the participants had the opportunity to listen to their recorded voices during and after the process, Fast considered it ethically necessary to let them listen to the selected sounds before making the artwork public. However, many of the participants had been discharged by that time. The situation was ethically ambivalent because Fast had not added to the informed consent forms permission to send them the recorded sounds after the fieldwork, which would have also required more personal information (such as an address). Moreover, it could have reminded them of their distress and suffering. Finally, Fast sought to inform the participants of the publication and asked whether they wanted to listen to the sounds but was no longer able to reach them. This difficult ethical issue was related to the potential risks and benefits of artistic research in a health context: how to balance the artistic work, actualised with the participants, and the commitment made to them against the potential benefits that the artist-researcher might derive from presenting the artistic or academic results of the research.

In sum, arts-based and artistic research in care contexts posed ethical dilemmas over professional boundaries where various professional responsibilities, rights, and access to information were negotiated. On the one hand, professional boundaries might have helped to understand where medical treatment came into an end and artistic activity began. On the other hand, the hybrid position of the researcher may have overstepped the rigid boundaries between different disciplines and discourses and create expectations about objectives and methods among participants. The relationships between all parties involved in the research projects were regulated by context-specific ethical procedures, but arts-based and artistic research, we believe, also leaved room for new boundary zones to emerge.



## Considering vulnerability in artistic and arts-based research

The notion of vulnerability is a central ethical feature of boundary work in the social and healthcare sectors in general, and we as researchers are aware of the complexities and ethical tensions surrounding the term “vulnerable”. On the one hand, vulnerability is an “existential condition” since we are all subject to accidents, illnesses, and ageing and need the support of others at various stages of our lives (Butler, 2016). On the other hand, the notion of vulnerability can be linked with problematic and stigmatising ways of categorising people, thus reinforcing precarious and unequal social/power structures (Butler, 2016).

Working in disability services as a dance pedagogue, Jaakonaho has encountered individuals with different needs and abilities, including people with more severe disabilities, some of whom are non-verbal. In her pedagogic practice, Jaakonaho felt that she needed to observe individual differences and needs to make the activity accessible to everyone involved while at the same time not underestimating or infantilising the participants. People with disabilities are often labelled vulnerable, and their vulnerability is often tangible in physical activities, such as dance. However, being aware that disability is shaped by the restrictions and attitudes of the environment (Shakespeare, 2018), Jaakonaho did not want to reinforce potentially disempowering assumptions, such as a rigid category of “vulnerable people”, in her work.

In Fast’s research, the non-verbal vocal work with the patients brings the perspective of vulnerability to the foreground (Fast, 2020). This versatile concept in psychiatric healthcare refers to psychic vulnerability, pointing to existential, environmental, and cultural aspects that threaten and frame an individual’s mental health (Fuchs, 2013). In shared vocalising, Fast approaches vulnerability through relationships. She seeks to actively open her research to the sensate dimensions of experience and communication, expecting that allowing oneself to become vulnerable might offer access to the experience of connection, provided that the participants feel emotionally safe. The artistic research tool for facilitating the conditions for vocal-affective attunement (Fast, 2020, 2018), in reference to Stern’s (Stern, 1985) “affect attunement”, by non-verbal vocalizing, created a particular entanglement between the ethical and aesthetic aspects (see Guattari, 1995), where the researcher’s own hybrid position became significant. Fast was able to invite the participants to attune to shared vocalising by opening up and allowing herself to become vulnerable first. From an ethical point of view, vocal-affective attunement requires constant movement between the ethically responsible subject position and affective encountering, and creates a particular immanent ethics of sensorial attunement (Fast, *in press*; Leppänen & Fast, *in press*).

Also, in Jaakonaho’s research practice, she was non-verbally *attuning* to the energy levels, gestures, rhythms, and movement qualities of the disabled participants, as a way to create conditions for ethically sensitive encountering. As a practitioner, Jaakonaho is informed by her studies of dance movement therapy, in which the notion of “affect attunement” (Stern, 1985) is key. Jaakonaho also addressed her own vulnerability and interdependency through the themes of the artistic parts of her research, aiming to approach the questions of disability and ability as something that everyone could relate to (see Jaakonaho & Junttila, 2019).

Koivisto's work emphasises the importance of understanding relevant ethically and emotionally complex music practices (Allsup & Westerlund, 2012; Koivisto & Tähti, 2020) and research approaches in hospital wards. Touching on questions which resemble the ethics of attunement (Fast, *in press*; see Lipari, 2014), she has argued in her doctoral research, that *silent participation* (Koivisto & Laes, *in press*) and emotional processes of the patients and their families should be better acknowledged in the everyday life of the hospital wards. Furthermore, creative and emotional awareness within boundary work highlights the empathetic approach and vulnerability of arts professionals and arts-based researchers. This means engaging with thoroughly ethical reflection of one's experiences and practices as a professional. Ethical engagement is crucial in preventing the exploitation of others. It may also support to practice professional self-care, instead of work-related stress and pressure (Hoover, 2021; Koivisto, 2021).

Considering the ethical attunement and position of the researcher, in many situations, it was nearly impossible to collect qualitative observation data in a rigorous, medical manner during intensive musicking practices. Instead, the musicking situations, being so sensitive and intimate in nature, invited Koivisto to make a conscious decision to take part in the musicking. This led to a process of reflection on ethics in which the distance and proximity of her own position in the inclusive, shared space in the ward were constantly rethought. The musicking moments seemed to have the power to suspend the role of patients as objects of care and support their self-determination but also to allow the researcher to move from her position as an observer to a more involved, reflexive participant.

As our reflections show, in artistic and arts-based research in care contexts, we are often faced with vulnerability: our own and others'. This brings us to questions of agency, self-determination, and power. It is important to reflect on these issues in depth to avoid the exploitation and appropriation of others' experiences and ideas.

### **Ethics, evidence, and the notion of well-being**

The ethical concerns that have emerged in our research highlight the epistemic complexity of the concepts of well-being and evidence. When conducting artistic and arts-based research in care contexts, methodological choices become entangled with questions regarding the notion of well-being, how we understand what is good for people, and what kind of knowledge is seen as valid in providing care and support to improve quality of life.

All three researchers dealt with embodied and implicit knowledge. Koivisto was involved in sensitive and intimate musicking situations as an arts-based researcher. Through her case studies, she found that embodied and emotional knowledge, and making implicit knowledge more explicit were key aspects of healthcare musicians' hybrid and ethically responsible professionalism. In Jaakonaho's and Fast's research, knowledge emerged from and was articulated through artistic, embodied, experimental, and performative practices, which is characteristic of artistic research (Borgdorff, 2012; Hannula et al., 2014; Varto, 2018). Although in Fast's research, artistic practice was considered the primary mode of knowledge production, knowledge was generated in a transdisciplinary manner using qualitative methods and psychiatric questionnaires.

Jaakonaho's research was also informed by the methodological discourses of post-qualitative research. Post-qualitative research, introduced by St. Pierre, is a mode of enquiry inspired by the Deleuzian philosophy of immanence, which ontologically places life, thought, being, and nature on a single surface of existence. Following this ontology, post-qualitative research rejects conventional, predetermined research methods, practices, and categories. (St. Pierre, 2011).

All three researchers considered their understanding of well-being in relation to their research. Koivisto found the concept of cultural well-being to be a useful tool when engaging in interdisciplinary conversations and interprofessional planning. It helped her facilitate a mutual interprofessional language and collaborative knowledge building taking place between the artistic and healthcare areas, as well as between the social, nursing, and medical sciences. The notion of cultural well-being as one's own experience of and connection to culture and the arts (Lilja-Viherlampi & Rosenlöf, 2019), which improves one's well-being, created a sufficiently common conceptual space for interprofessional work. Through this lens, with the help of healthcare musicians, an interprofessional space was created, where Koivisto could engage and enter ward musicking as a researcher.

Fast approached cultural well-being from the perspective of psychic suffering. One of the main aims of her research was to create new sensibilities in psychiatric care. The discussion of sensibility in the context of cultural well-being allows one to move from experienced well-being towards the complex relations that create the conditions for well-being. The epistemological, methodological, and sensorial boundary work in Fast's research provided tools for understanding the collaborative potential and shared goals of artistic research and psychiatry. Human suffering can often be manifested as obmutescence. Challenges in verbal communication are also considered in the diagnostic classification of mental disorders (Terveyden ja hyvinvoinnin laitos, 2012, see for example, p. 140). In shared vocalising, the participants were able to create connections during non-verbal communication. The patients reported, for example, feelings of increased vitality, which were also evident in the recordings. Their capability to strive for well-being increased. However, tensions with the psychiatric care system also emerged because such interactions also require emotional and conceptual work on the part of staff members and raise questions about how to create the conditions for attuning to affective encountering amid challenging psychiatric work.

According to Fast's findings, the shared voice of the patients, the artist-researcher, and the staff members in the artworks may also be seen as a sensate mode of boundary spanning, as it created a peculiar environment where the distinctions between inside and outside were blurred: one could not hear a difference between those who were receiving and those who were providing help, which highlighted the importance of the ethics of attunement. The blurred boundaries between people felt uncanny to some staff members. However, the bodily felt aesthetic experience also created shared meanings and human-to-human communion among the actors. (Fast, 2018)

In Jaakonaho's research, the notion of well-being is connected to questions regarding the value and meaning of artistic activity in disabled people's lives in relation to their well-being and cultural rights. In the context of disability, the question of well-being is complex. In critical disability studies, certain neoliberalist uses of the concept of well-being can be problematic, as they may reinforce ableist and normative notions of health and good life. Campbell (2009) defines ableism as a "network of beliefs, processes and

practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human” (p. 5). Those who cannot or will not attain normative expectations of well-being can experience such norms as exclusive and even stigmatising. Politically, these tensions can be seen as an effect of neoliberalism and its ostensible agenda of diversity, which suppresses disability as a “state of abjection” (Davis, 2014, p. 9).

According to Jaakonaho’s findings, well-being appears to be an affective interpersonal and intrapersonal experience, manifested in moments of shared joy and laughter, in embodied experiences that destabilise fixed subject positions, and in affirmative experiences of seeing and being seen, of moving and being moved (see Jaakonaho & Junttila, 2019). This suggests that, regardless of the institutional context, experiences of well-being are often rooted in meaningful, embodied connections within one’s environment.

Cultural well-being, approached through boundary work between artistic research and the medical and social sciences, is a complex phenomenon that simultaneously affects the affective, sensorial, societal, and political levels. When well-being is understood in such a relational and multifaceted way, the role of research expands from the expectation to produce evidence to a need for reflection on embodied and situated experiences, practices, and interactions in specific socio-material and institutional environments.

## Conclusion

In this article, we explored arts-based and artistic research in health and social care as a form of boundary work and considered the ethical issues emerging from it. By collaboratively reflecting on procedural ethics in social and healthcare settings, we identified ethical challenges caused by the strict code of conduct on privacy and other similar codes. Sensitivity and awareness as part of ethical attunement within different working cultures and institutional procedures are essential in arts-based and artistic research. Researchers working in such boundary zones should be aware of and able to reflexively cope with different research protocols for medical and non-medical research in the same contexts.

Ethical reflection provides transparency and clarity in communication so that everyone involved understands their role, has all the relevant information, and has a chance to contribute to the process actively. Artistic activities can provide affirmative experiences and meaningful connections in people’s lives. However, in introducing, mediating, and facilitating these activities, it is important to be aware of the complex and often asymmetrical power relations between participants, facilitators, and other professionals. When artistic-pedagogic research processes are managed with ethical sensitivity and awareness, artistic agency can be shared between artist-researchers and participants. This challenges the traditional individualistic view of the artist, as well as an exclusive notion of art as something that belongs only to talented, skilled, and abled people.

We discovered that many key ethical concerns in artistic and arts-based research in care contexts are connected to the notion of vulnerability. When negotiating our roles as researchers in sensitive contexts, we faced our own and others’ vulnerability. Collaboratively reflecting on these experiences, we became aware of the complexities and ethical tensions surrounding the term “vulnerable”. This led us to tackle pivotal

questions about agency, self-determination, and power, which are important points of reflection not only in research but also in encounters between the arts and health or social care in general.

In terms of epistemology, arts-based and artistic approaches may expand the idea of what we consider evidence of cultural well-being in care contexts. We agree that it is important to develop methodologies to measure the impacts of artistic activities in order to provide a more solid justification for these practices in health and social care. However, this should be accompanied by theoretical and methodological developments in the fields of the social sciences and artistic enquiry. We suggest that the concept of cultural well-being can function as such a boundary zone, where the negotiation of what is evidence could be explored in interdisciplinary encounters. In this article, concepts emerging from our own research contexts and theoretical frameworks, such as musicking, vulnerability, human sensibility, and disability, contributed to a holistic view of well-being. When well-being is approached through these concepts, the focus shifts from individual to relational well-being – to the complex societal and even political relations that create the conditions for well-being in the first place.

Considering the field of boundary studies more generally, this article advances the idea of how different (social) worlds and fields may communicate, but still preserve their intrinsic nature and balance (see Van Egmond & Zeiss, 2010). Articulating and negotiating the ethical concerns that arise in boundary work and research can promote a more nuanced understanding of the power relations at play in practices that cross the sectoral boundaries in societies. We may not always have answers to the ethical questions that we encounter in such a complex field of work. However, working to become more aware of these questions and striving to articulate and negotiate them in a dialogical manner can change the ways in which we manage these situations when and where they are embodied. Awareness of ethical concerns can make us researchers and practitioners more open and flexible and more prepared to change our plans and listen to others rather than rigidly holding on to our positions.

## **Ethical considerations**

The research projects presented in this article have received ethical statements from the University of the Arts Helsinki's Ethics Committee (Koivisto) and The Ethics Committee of the Helsinki and Uusimaa Hospital District (Jaakonaho, Fast). Research permits were obtained from the Helsinki and Uusimaa Hospital District (Koivisto, Fast), the City of Espoo (Koivisto) and a large operator of private disability services (Jaakonaho).

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