Approaches: An Interdisciplinary Journal of Music Therapy
Special Issue 17 (1) 2025 – Ethical Questions in Transforming Music Practices
ISSN: 2459-3338
https://doi.org/10.56883/aijmt.2025.616

ARTICLE

Noise, doubt, empathy or surprise? A qualitative collective self-study exploring the phenomenon of disruption in clinical trials

Kjersti Johansson
Centre for Research in Music and Health, Norwegian Academy of Music, Norway

Tone S. Kvamme
Centre for Research in Music and Health, Norwegian Academy of Music, Norway

Kristi Stedje
Centre for Research in Music and Health, Norwegian Academy of Music, Norway

Runa Bosnes Engen
Lindeberghjemmet, Norway

Unni Tanum Johns
University of Oslo, Norway

Solgunn E. Knardal
NKS Olaviken Psychogeriatric Hospital, Norway

Anette D. Moltubak
Molde University College, Norway

Hanne Cecilie Webb Aamodt
Asker kulturskole, Norway

Karette Annie Stensæth
Centre for Research in Music and Health, Norwegian Academy of Music, Norway

ABSTRACT

Disruptions, i.e. things or events that interrupt the normal or expected, may be experienced as something positive, but also as something negative. They are an integral part of clinical trials, often representing ethical challenges. As researchers, we are the agents of disruption: we intervene in participants' lives by implementing interventions and collecting data; we engage stakeholders and ask colleagues for support. How do these disruptions affect the researchers themselves? In this study, we explore disruptions from a researcher's perspective in a qualitative self-study of our experiences while working together on an international randomised controlled trial. The data comprises qualitative interviews with us, the music therapy research team in the Norwegian partner institution of the trial. The interviews were analysed using a collaborative reflexive thematic analysis. Four themes, representing different types of disruption and qualities in our experiences of them, were identified: *background noise*, *rejection*, *empathic disruption*, and *disruptive dissonance*. These themes share the characteristics of being relational, sometimes ambiguous, and influencing each other, requiring interpretation in context. This complexity makes them challenging to define and navigate. We argue that continuous reflection on different disruptions and negotiation of their boundaries are vital to ensure high ethical research standards and to support researchers' self-care.

KEYWORDS

disruption,
clinical trials,
self-study,
ethical dilemmas,
researchers' self-care

Publication history:
Submitted 20 Nov 2023
Accepted 16 Feb 2025
First published 18 Jun 2025

Publisher: Queen Margaret University Edinburgh | Centre for Person-centred Practice Research

AUTHOR BIOGRAPHIES

Kjersti Johansson, PhD, is a researcher at the Norwegian Academy of Music and a music therapist at Oslo voksenopplæring Nydalen, an adult special education centre. [Kjersti.Johansson@nmh.no] **Tone S. Kvamme** is associate professor of music therapy and a researcher at Center for Research in Music and Health (CREMAH) at the Norwegian Academy of Music. Kvamme is an experienced music therapy clinician in the field of dementia care and elderly health. [tone.s.kvamme@nmh.no] **Kristi Stedje**, PhD, is a music therapist, researcher and project leader at the Norwegian Academy of Music. She is an experienced music therapy clinician in the field of dementia care and elderly health. [kristi.stedje@nmh.no] **Runa Bosnes Engen** is a music therapist with long experience in the field of geriatrics, as a clinician in elderly and dementia care units, and as a lecturer and supervisor. [runa_be@hotmail.com] **Unni Tanum Johns** is Associate Professor at the University of Oslo, a licensed psychologist and music therapist from Guildhall School of Music. Her research is on affect integration through musical microprocesses. She has published articles, textbooks and book chapters, the latest in *Clinical Decision-making in Music Therapy* (2023, by Barcelona Publishers). [u.t.johns@psykologi.uio.no] **Solgunn E. Knardal** is music therapist at NKS Olaviken gerontopsychiatric Hospital. She is an experienced music therapy clinician in the field of dementia care and elderly health. [solgunn.elisabeth.knardal@olaviken.no] **Anette D. Moltubak** is a PhD candidate at Molde University College, Faculty of health and social sciences, with 15 years of experience as a music therapist. [anettemoltubak@gmail.com] **Hanne Cecilie Webb Aamodt** is a music therapist (MA) in the school of music and performing arts in Asker. She is an experienced music therapy clinician in the field of dementia care and elderly health working both in care homes and with people living with dementia at home. [hanne.cecilie.webb.aamodt@asker.kommune.no] **Karette Stensæth** is professor of music therapy and leader of Center for Research in Music and Health (CREMAH) at the Norwegian Academy of Music. Stensæth has a long publication list and has more than 20 years of practical experience as a music therapist. [karette.a.stensaeth@nmh.no]

INTRODUCTION

Disruption has become a buzzword in many fields, such as technology and business, where it is linked to innovation and growth (Christensen et al., 2015). The concept has also gained popularity in other areas, such as healthcare (Boston-Fleishhauer, 2015; Ganguly & Kumar, 2022) and education (Kirp, 2022). "Disruptive innovation" involves radical change; it seeks new solutions not simply by improving existing ones, but by disregarding the status quo and designing new solutions from the perspective of the consumer's or patient's needs (Boston-Fleischhauer, 2015). In research, disruption is sometimes seen as an ideal. The term "disruptive research" refers to research that introduces new approaches and poses fundamental questions that lead to innovative knowledge and new directions. Its opposite is "developmental" or "consolidating" research, which adjusts and improves existing knowledge or applies old theories in new contexts (Park et al., 2023). However, one could argue that any clinical trial represents a form of disruption. Often, the aim is to test an intervention that may, or may not, transform participants' lives or at least expand knowledge in the field of interest. As such, clinical trials can be seen as disruptive and transformative practices.

As a starting point for the exploration of disruption in this study, we suggest understanding disruption as an incident, big or small, that interrupts the normal or expected arrangement of things or the normal course of an event or activity (cf. an everyday understanding as found in dictionaries such as Merriam-Webster [n.d.] and Cambridge Advanced Learner's Dictionary & Thesaurus [n.d.]). This may include unexpected incidents, such as illness or an unexpected reaction, or planned intentional incidents, such as interventions or assessments that interrupt the normal course of everyday life. Disruptions involving phenomena, events, or reactions can be internal, such as symptoms of a diagnosis or illness, or external, such as natural disasters.

This study emerged from the authors' own experiences of working together in different researcher roles on a randomised controlled trial, the HOMESIDE trial (Baker et al., 2023a).[1] The trial, implemented during the COVID-19 pandemic, involved home-dwelling people living with dementia

[1] To avoid any potential misunderstandings, we will use "study" for the current research being presented in this article, and "trial" to refer to the HOMESIDE trial.

and their informal carers[2] in online music or reading activities. We are researchers in the Norwegian partner of this trial, and we are all trained music therapists. HOMESIDE was our first experience of being involved in a large randomised controlled trial, and in many of our national research team meetings, we discussed disruptions in the process.

On an overarching level, the COVID-19 pandemic disrupted both our team and the trial. Also, when interacting with people during the trial, we often felt that we were disturbing them. For example, when we completed various questionnaires with participants about their illness and well-being, provided online intervention training sessions, approached stakeholders to further recruitment, asked colleagues for support, contacted potential participants for screening, or scheduled participants for training sessions or assessments. In summary, there were many types of disruptions that affected us and our research process. For us, these disruptions and our ambiguous feelings related to them became so prominent that we felt the need to explore the phenomenon in depth, both to learn from it and to contribute to a deeper understanding of disruption as a phenomenon in research.

Our aim is to gain new insights into our work as researchers and thereby expand the understanding of disruptions in research. We wish to explore and describe different characteristics and qualities of disruptions that we have encountered. We hope this will be useful in aiding researchers and other professionals working within clinical trials and transformational practices to navigate and deal with disruptions. This article asks: *What types, characteristics, and/or qualities of disruptions can be experienced within a randomised controlled trial?* To investigate this question, we have chosen a qualitative, explorative, first-person perspective where we examine our own first-hand experiences of the phenomenon of disruption.

DISRUPTION IN RESEARCH

Disruption in research is a multifaceted phenomenon, of which there is a vast amount of literature. To limit the scope, we focused on literature that describes aspects comparable to the HOMESIDE trial, as the present study developed from our experiences within this trial.

Often, elements in the research process, such as assessments, randomisation procedures, or a strict protocol, are viewed as potential disruptions that can negatively affect participants' well-being. They represent participant burdens and risks, and researchers should aim to minimise disruptions (Kusch & Potthoff, 2019). Therefore, disruptions pose ethical questions that researchers, especially in clinical trials, must navigate (see for instance the Belmont Report on ethical principles and guidelines for the protection of human subjects of research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

Respect for individual autonomy is fundamental in all research involving human beings. Ethical issues involve the protection of the rights, safety, and well-being of the participants (Muthuswamy, 2013). The fundamental concern, says Muthuswamy (2013), "is whether and when it can be acceptable to expose some individuals to risks and burdens for the benefit of others" (p. 10). The concept of risk, continues Muthuswamy,

[2] Persons providing care for the person with dementia within the context of an existing relationship, such as a family member, a friend or a neighbour.

> is generally understood to refer to the combination of the probability and magnitude of some future harm. According to this understanding, risks are considered "high" or "low" depending on whether they are more (or less) likely to occur, and whether the harm is more (or less) serious. In research involving human participants, risk is the central organizing principle, a filter through which protocols must pass; research evaluated by ECs [ethics committees] that presents greater risks to potential research subjects will be expected to include greater or more comprehensive protections designed to reduce the possibility of harm occurring. (Muthuswamy, 2013, p.10)

The researcher-research participant relationship is also a relevant concept connected to disruption as a phenomenon. In qualitative research, such as interview studies, developing interpersonal relationships is seen as essential (Eide & Kahn, 2008). Here, the researcher and participant engage in a dialogic process that evokes memories and feelings that are remembered and reconstituted in ways that might not otherwise occur. Ethical issues arise when this relationship not only provides research data but also creates ethical disruptions, for example, by (unintentionally) having a therapeutic impact on the participant. According to Eide and Kahn (2008), this demonstrates how intimate dialogue might overstep personal boundaries.

Another aspect of disruption, particularly in controlled clinical trials, involves how researchers need to "control" potential disruptions so that they do not negatively affect the research and its results. This is relevant to ensure standards such as high treatment fidelity and controlling assessor bias. This can be especially challenging in studies that move beyond traditional clinical settings by offering home-based interventions. Disruptions may be more frequent when the research takes place at home, in an environment that is not easily controlled and may be filled with memories. After all, a home is a private space that houses memories and psychological ambiance, such as mood, feelings, and emotions.

When compared to a more neutral clinical setting, a home might appear to be "messier", posing challenges for research implementation. Although there are several potential benefits to using home settings, such as participant convenience, there are also specific challenges related to controlling adherence, collecting data, and more. While some suggest that participant disruptions are reduced, others point to the possibility of an increased burden, for example, making participants responsible for recording more data (Coyle et al., 2022; Lalanza et al., 2023; Randell et al., 2021).

So, while researchers impose disruptions on participants and simultaneously try to control research disruptions, they should also ensure that participants and others involved are treated in a respectful and ethically responsible manner. This is especially important in studies involving persons living in vulnerable life situations, such as people living with dementia, who may have a lower threshold for the stress that disruptions can cause.

Dementia is, of course, a disruption primarily present in the everyday life of the person affected and their closest family and friends, but it may also pose disruptions in a clinical trial. Sometimes it affects the research process more, sometimes less, depending on if and how the dementia symptoms affect the present moment. Persons with dementia may, for instance, exhibit Behavioural and Psychological Symptoms of Dementia (BPSD) that are disruptive to caregivers and others in the environment (Gitlin et al., 2012). Additionally, the psychological and emotional impact of dementia can be overwhelming both for caregivers and those who are involved in the research. It may be

challenging to witness how a person's feelings, behaviours, thoughts, and responses are negatively affected by dementia (i.e., World Health Organization, 2023). Dementia stigmas may amplify this disruption. Additionally, the psychological and emotional impact of dementia can be overwhelming for those who are involved in the research. Seeing and relating to how a person's feelings, thoughts, and responses are affected and how it leads to deterioration in cognitive function, changes in mood, emotional control, behaviour, or motivation can be challenging (i.e., World Health Organization, 2023).

Disruptions can also occur in other ways. Several dementia trials, for example, utilise standardised questionnaires to measure the impact of interventions. Many such questionnaire ask participants about sensitive areas involving their overall functioning. These might include questions about disease, memory and cognitive functioning, and emotional states (depression, anxiety, distress, etc.). The person answering might experience these questions as disruptive reminders of things they struggle with and/or are no longer capable of doing. Garrels et al. (2022) found that witnessing difficult life stories and circumstances during research interviews with vulnerable participants also had an emotional impact on the researchers. This can be psychologically demanding and often requires balancing proximity and distance, which can be emotionally taxing. They highlight the need for institutional support and self-care for researchers.

A recent external research disruption is the COVID-19 pandemic. In their systematic review, Sathian et al. (2020) found that COVID-19 disrupted clinical trials largely by delaying subject enrolment and creating operational gaps, which in turn had a negative impact on trial programs and data integrity. They describe how, globally, most sites conducting clinical trials, other than COVID-19 trials, were experiencing delays in timelines and a complete halt of operations due to the pandemic. Therefore, COVID-19 also affected clinical research outcomes.

Further, infection control policies such as physical distancing demanded that social research, which tends to require direct interaction, be mediated through online-based applications. In a study on ethical challenges in clinical research during the COVID-19 pandemic, Bierer et al. (2020) found that, although there are issues with confidentiality, privacy, data integrity, and safety that need to be considered, remote visits also had some distinct advantages. These advantages included optimising participant convenience, reducing financial costs, and better use of time. These factors may even promote retention in clinical trials. However, this did not change the fact that participants appeared to appreciate the support that in-person visits provided. A recent study comparing face-to-face conversations to online (Zoom) interactions found significant differences, with in-person interactions showing increased gaze time, arousal as indicated by pupil diameters, theta power, and cross-brain synchrony, suggesting an increase in reciprocal exchanges and social cues. This suggests that facial expressions online do not engage social neural circuits as effectively as in-person interactions (Zhao et al., 2023). These two studies highlight how online delivery can be a viable option for inclusion and continuation, but also a disruption to important social interaction.

As one can see from the literature, disruption is often referred to from the perspective of the participants or as a result of external circumstances. Little focus seems to be on how the researchers implement, experience, and navigate disruptions. This surprised us, given that we, as researchers, are the *agents of disruption*. It also gave us another rationale for exploring our own experiences with disruption more in-depth.

CONTEXT AND RESEARCHER POSITIONALITY

The foundation for this study is our own experiences with a clinical trial research process that challenged us, prompting a more systematic exploration. Because personal experiences are central to the study, we will provide the reader with background information about who we are and the experiences that led to this study.

First, we are Norwegian music therapists trained in traditions emphasising improvisational, cultural, relational, and critical aspects, often referred to as *humanistic*, where the needs and interests of the Other are central to our actions and reflections (Ruud, 2010). A humanistic outlook, according to Ruud (2010, pp. 15–20), emphasises the music therapist's 1) care for the individual, 2) empathy, 3) critical mindset, 4) self-determination, and 5) use of symbols, metaphors, and meanings. For this study's theoretical framework, we draw on this tradition and emphasise a relational, intersubjective perspective (Trondalen, 2016). We have coupled this with a creative understanding of *responsiveness*, as described by Stensæth (2017). Responsiveness, she claims, involves viewing human interaction as situated, personal, and improvisational, thus open to surprise and doubt. Intersubjectivity for us refers not only to the process and product of sharing experiences and understanding but also to recognising that it involves uncertainty and unexpected insights. Further in this article, we will reflect on the potential impact our music therapy tradition might have had and use these theoretical perspectives to interpret our findings.

As mentioned, the basis for this study is our experiences working together on the HOMESIDE trial, an international randomised controlled trial involving five countries (Baker et al., 2023a). The primary aim of this trial was to investigate the effects of a home-based caregiver-delivered music intervention on behavioural and psychological symptoms of dementia. The HOMESIDE trial required substantial commitment from the participants, which might have been perceived as burdensome. We were conscious of this from the outset and aimed to minimise participant burden and disruption. Our initial interest in and understanding of the phenomenon of disruption were likely influenced by this sensitivity. We have also considered whether being Norwegian might have accentuated our caution to disrupt, as Norwegian culture has a "distance rule of politeness" that values respecting others' private space and avoiding unnecessary disturbances (Rygg, 2017).

Further, we were all inexperienced in conducting large quantitative clinical trials. Some of us had substantial experience as qualitative researchers, while others were new to research. In the process of coming to grips with implementing the trial, we had unsettling experiences of either being a disruption or being disrupted. Naturally, COVID-19 was a major disruption. It meant shifting to remote online delivery of interventions and assessments, instead of in-person home visits. This change significantly altered our interactions from what we were used to, as we were accustomed to responding to music therapy clients and research participants directly and in person—with empathy and intuition derived from being in the same physical space. This inability to act as we were trained may have heightened our sensitivity to whether our research, compounded by the pandemic, was a disruption to others.

We became increasingly aware of the continuous presence of disruption as a phenomenon. However, a clear research interest was not articulated until the *European Music Therapy Conference 2022* launched its call for abstracts with the theme "Music Therapy in Progress: Please Disturb". This

theme and its spotlight on "please disturb" resonated with us, sparking our curiosity and inspiring us to examine what we perceived as an unsettling phenomenon more closely.

METHODOLOGY AND METHODS

For us, elaborating on the study's methodology and choice of methods involved dynamic exploration in the research process. To be transparent about this, we will describe how it unfolded. From the onset, we chose a qualitative, explorative methodological approach with a first-person perspective (Hunt, 2016) for our study. Our research process developed as a group collaboration involving multiple first-person perspectives, a type of collective self-research where the "group examines their own experiences through both individual and group means" (Hunt, 2016, p. 460). In other words, we examined ourselves both from the inside and the outside in an intersubjective exploration emphasising collaboration and dialogue. Throughout the process, we also emphasised our researcher reflexivity. We acknowledge and draw attention to ourselves as researchers and as part of the world we study. We do this to remind ourselves that we are involved in our research as subjects, not objects, and to critique, evaluate, and understand how our subjectivity and context might have influenced the research (Olmos-Vega et al., 2022).

In our exploration, we first found inspiration and justification for emphasising our lived experiences, as described by Van Manen's (1990) phenomenology. He focuses on the nature of our lived experiences and suggests investigating them through engagement in discussions and reflections before transferring them into written words, while trying to balance the research by exploring both parts and the whole (van Manen, 1990). However, we have not used his methodological framework throughout the process.

We also knew early on that we wanted to explore and reflect on the phenomenon of disruption together as a group, as we felt that each other's inputs and support were both stimulating and helpful in uncovering its meaning. We therefore chose focus group interviews as the method for generating data. The focus group aims to bring forth different viewpoints and is well-suited for exploratory studies investigating complex and poorly understood topics, as group interaction stimulates sharing and self-disclosure and elicits more spontaneous views than individual interviews (Brinkmann & Kvale, 2014; Krueger & Casey, 2015; Morgan, 1998).

In retrospect, through our ongoing exploration and the peer review process of this article, we have become aware that much of our approach aligns with self-study research in general and collective autoethnography in particular. Self-study has recently become more accepted as a way to expand our ways of knowing (Kitchen et al., 2020). The term self-study was defined by educators Hamilton and Pinnegar as

> the study of one's self, one's actions, one's ideas, as well as the 'not self'. It is autobiographical, historical, cultural, and political and it draws on one's life, but it is more than that. Self-study also involves a thoughtful look at texts read, experiences had, people known, and ideas considered. (Hamilton & Pinnegar, 1998, p. 265)

In the present study, our own feelings, actions, stories, and music therapy culture within a clinical trial were investigated to understand their connections with and relationship to our experiences of disruption. More specifically, our self-study approach aligns with collective autoethnography (CoAE), as described by Karalis Noel et al. (2023). CoAE combines principles of autoethnography, participatory research, and narrative inquiry, offering advantages to researchers seeking to explore their shared experiences, positionality, and responses to phenomena. CoAE also fits well with our ideal: it is a democratic methodology that emphasises co-constructing in-depth exploration of narratives to grasp nuanced and multi-layered details of a phenomenon. CoAE enlists multiple researchers' collective interpretation derived from group interviews and shared meaning-making. As a method, it is iterative rather than linear, which has been the case with our study as well. Karalis Noel et al. (2023) describe CoAE as a six-phase approach. Our study has also proceeded along these steps. We 1) co-constructed our research and interview questions, 2) coordinated and scheduled the interviews, 3) conducted and transcribed the interviews, 4) coordinated and conducted data analysis, 5) reviewed themes, and 6) co-constructed the narrative. In the following, we will not explicitly refer to these six phases, although phases 1-3 are covered under data generation and phases 4-6 are covered under data analysis.

Data generation

To avoid double roles in the interview setting and to ensure everyone's experiences were captured similarly, we decided to have a moderator who was not part of the clinical trial research team. When selecting a moderator, we emphasised their moderating skills (Krueger & Casey, 2015) and chose someone with extensive experience with interviews, focus groups, research, and music therapy, making her suitable to lead these exploratory discussions. To be able to catch nuances in our interview responses, it was also important for us that the moderator, who was also trained as a music therapist, was part of the national culture and shared our school of thought. The moderator led the interviews and oversaw the data generation. She also took part in writing the paper, elaborating on the findings.

We then created two focus groups, with four participants per group. This is a relatively small focus group, but it was appropriate as we aimed to understand our experiences that warrant in-depth insights. In addition, we anticipated that we all would be comfortable talking in the groups and have much to share, being passionate about the topic. These characteristics all pointed to a small group being preferable, providing enough opportunities for all to share (Krueger & Casey, 2015).

The focus groups consisted of trial staff, who were all music therapists, limited to one participating country, Norway. This delimitation prioritised similarities within the group. We believe this homogeneity was an advantage when exploring a not well-defined phenomenon, giving us the opportunity to go in-depth without being disrupted by differences in language, discipline knowledge, etc. At the same time, our different roles as managers, supervisors, assessors, or music intervention trainers, and differences in levels of experience, provided enough variation to explore diverse aspects and experiences of disruptions.

The moderator and first author held preparatory meetings to ensure that the moderator had a sufficient understanding of the study's purpose and topic, as well as the different researcher roles among the trial staff. They also developed a flexible interview guide together, to be used in a semi-structured manner. Examples of questions included: "Could you start by talking a bit together about your own experiences of disruptions that are present in a clinical trial like the one you are working on?", "What are your associations with the term 'disruption' in research?", "Have you experienced being a disruption/being disrupted in the trial?", "How did you experience being a disruption/being disrupted?", and "Are there any other words or concepts that better describe your experience, or that complement the understanding?"

We then separated into groups based on trial responsibilities: one group where the participants had responsibilities related to the interventions and another where participants had responsibilities related to assessments (screening, baseline, and follow-up data collection). This division ensured the characteristic homogeneity of focus groups, while differences in other responsibilities, which most of us had, provided sufficient variation among participants to allow for contrasting opinions (Krueger & Casey, 2015). The division also had a practical reason. As the clinical trial was still ongoing, we needed to ensure that assessors did not accidentally get information about what interventions the trial participants received. Such accidental unmasking might also have been a concern for us had we not separated intervention trainers and assessors. Potentially, this could have stressed us and disturbed the flow of the conversation.

Due to illness, the clinical trial project leader could not participate in her scheduled focus group. To include her perspective, she was interviewed individually afterwards. This could be considered a weakness, as her voice might be more prominent in the data. However, we were mindful of this during the analysis, ensuring that the themes were relevant to all study participants. In hindsight, we believe that removing her from the focus group might have been beneficial, as power relations between clinical trial research team members and the trial project leader could have affected the focus group dynamic.

The intervention focus group lasted 2 hours and the assessor group 2.5 hours. They were video recorded to ease transcription. The individual interview lasted 1 hour and 35 minutes and was audio recorded. The interviews were all transcribed verbatim before analyses (106 pages, font Times New Roman, size 12, single spacing).

Collaborative reflexive thematic analysis

The interviews were analysed through a dialogical collaborative process in which we worked together as a group for over a year. We developed an analysis procedure inspired by Braun and Clarke's (2006; 2022) reflexive thematic analysis — a methodologically open approach that aligned well with our research values, such as embracing researcher subjectivity as a resource and emphasising researcher reflexivity. However, we made some adjustments to better suit our collective group process. The analysis was primarily inductive and semantic, though a latent approach was also used at times. Below, we present the phases and steps involved, with the steps inspired by Braun and Clarke noted in parentheses and italics.

Phase 1: A work group with representatives from all interviews (KJ, KAS, KS, TK) worked through the following steps:

- Individual open listening to the interviews and reading of transcripts while making notes of initial observations and insights (*familiarisation*).
- Collaborative analysis meeting: As we value a collaborative and dialogical process in our analysis, we decided to move quickly to a group meeting instead of an individual coding process. In the meeting, we discussed our initial observations and insights, reviewed selected transcript parts, and identified potential themes (*generating initial themes*).
- Individual review of transcriptions, notes, and initial themes (*generating initial themes*).
- Collaborative analysis meeting: Two of the work group members (KJ and KAS) had a second collaborative meeting, while two members (KS and TK) provided any written comments before the meeting. In the meeting, the themes were reviewed, and we identified preliminary themes (*developing and reviewing themes*).

Phase 2 included the remaining members of the research study team (except for the interview moderator, UJ) and comprised the following steps:

- Individual open listening to the interviews and reading of transcripts while making notes of initial observations and insights (*familiarisation*).
- Individual review of preliminary themes with written feedback to authors KJ and KAS (*developing and reviewing themes*).
- KJ and KAS had a third collaborative meeting and adjusted themes in accordance with feedback from the group (*refining, defining and naming themes*).

Phase 3 consisted of working together in pairs to create theme descriptions and illustrative examples of the themes. This phase included the same team members as phase 2. We drew on specific experiences, events, and encounters from the clinical trial to aid the construction of these descriptions but made sure to anonymise any information about trial participants. The themes emerged and became clearer during this work, and in some instances, minor adjustments were made after group discussion (*refining, defining, and naming themes*).

Phase 4 was writing the paper and elaborating further upon the themes (*refining, defining, and naming themes* and *producing the report*). The first draft was written by two authors (KJ and KAS). All authors then gave feedback, and edited and reviewed the manuscript, including descriptions of themes, interpretations, and reflections.

Ethical considerations

This study was approved by Sikt – Norwegian Agency for Shared Services in Education and Research (ref. 871206) and the regional committee for medical and healthcare research ethics REK sør-øst (REK; 2019/941). We each provided written informed consent to participate in the study. We emphasised that each could decline participation or withdraw later without it affecting their role

in the trial we were working on. All study participants also wanted to be co-authors in this study and we therefore agreed that we would not be anonymised.

We were mindful that we undertook this study based on our experiences of meeting and working with participants in the HOMESIDE trial. The trial participants were not participants in the current study and did not receive information about it. Any examples and descriptions of encounters have been provided in an anonymised form. We committed to this approach before the interviews, aiming not to disclose any identifiable information about trial participants during the interviews. We have also carefully reviewed the manuscript to ensure the anonymity and respectful presentation of trial research participants. Colleagues, stakeholders, and other involved parties in the trial may also be indirectly described in our experiences. We have made every effort to ensure their anonymity and respectful representation.

FINDINGS

Theme 1: Background noise

This theme refers to how disruptive factors that permeate the implementation of a clinical trial can create a type of background noise to the research or to the researchers' perception of the "ideal" research progression and implementation. This background noise affected our concentration, which in turn could disturb our reflections and inhibit our actions. The background noise elements were present throughout the trial—sometimes lying beneath the surface, other times coming to the fore—but always maintaining a continuous presence that, metaphorically speaking, created a background noise for us and within us. Factors that most trials have in common include economic issues and obligations to funders and employers, such as reports and dissemination, with due dates that may not always be convenient for the researchers. In our trial, additional factors included the widespread disruption caused by the COVID-19 pandemic, ongoing difficulties with recruitment (Baker et al., 2023b), and several "small-scale disruptions", such as technological issues with online delivery, or problems with coordinating assessments, training, and interventions, and ensuring tasks were done in the right order and at the right time as described in the protocol.

These disruptions created a continuous background noise for our work and within us as researchers, serving as a source of worry and stress, and sometimes interfering with our actions and interactions with trial participants or other collaboration partners. For instance, difficulties with recruitment could leave us feeling disheartened and reluctant to reach out to stakeholders or potential participants, as we anticipated encountering challenges.

Dementia created its own background noise throughout the entire trial. Although it primarily affected the trial participants, it also impacted us as researchers. Dementia is a disturbing condition where difficulties are often understated, and the loss of memory, language skills, and oversight over one's past, daily life, and future can constantly affect the research process. Naturally, we observed that participants' symptoms could worsen, leading some to move to nursing homes or other care facilities. Conducting research with elderly and sometimes frail participants meant acknowledging that their general health posed an ongoing challenge. This could lead to health-related adverse events such as sudden deterioration, hospital admissions, surgery, transitions to institutional care,

and sometimes death. (Of course, not all participants were frail or had health issues simply because of their age; many were active and in good health.) Even though we were prepared for adverse events and health issues, we experienced a sense of disruption within ourselves, fearing these events might occur. This fear was twofold: we sincerely wanted the trial participants to feel well and not experience health issues, and we also did not want any issues to impact our research and our obligations to funders.

Additionally, many of us feared being a source of stress to the trial participants, placing an additional burden on them in an already challenging life situation. In this study's interviews, we discussed that our fear was perhaps reinforced by another constant background noise: the online delivery mode. By not visiting the participants in-person, but only remotely, we lost much information from the home context. Additionally, online interaction excluded us from fully sensing the participants' feelings in the same way as being physically present, preventing human touch or synchronous musical interaction in real time—elements that we, as music therapists, are accustomed to and respond to. As such, the online delivery mode should perhaps not be characterised as noise, but rather as a disruptive void. In this void, we missed important information, and something was lacking to complete the interaction. This void caused worry and uncertainty for us, creating a background noise within us as researchers. We were also aware that video calls could potentially be confusing for people living with dementia. In this sense, dementia and online delivery combined to create an extra level of background noise in our work and our contact with the participants.

Theme 2: Rejection

By the term "rejection", we refer to experiences of negative disruptions—incidents that we felt as rejections in one way or another. Such experiences were new and surprising for us as first-time clinical trial researchers, and ones we rarely encountered as music therapists.

The rejections differed in type and intensity. Some were mild and involved misunderstandings, such as when we had challenges explaining the research in an understandable way to potential new trial participants or when they met us with general mistrust of the research. Often, but not always, such disruptions ended with a decline to participate. In the recruitment work and screening of potential participants, the amount of commitment required was often met with scepticism, and we felt that too much "pushing" (or disruption) from our side could create reluctance in them. Other times, we were simply left without any response to our attempts at making contact, creating a feeling of rejection without us actually knowing if this was the case.

Other rejections were more intense. They could include confrontations, catastrophic reactions, and even hostility or aggression. For example, some participants or stakeholders had issues with certain parts of the research, expressing a strong dislike for the online delivery and questioning the research's integrity. Other participants were reluctant to answer some of the outcome measures, which required researchers to be flexible while still obtaining sufficient data.

We also experienced a few catastrophic reactions to the Mini Mental State Examination (MMSE), a standardised tool to assess cognitive impairment, where the participant living with dementia had a strong negative emotional response to the assessment. In a few cases, we also

observed caregivers struggling emotionally while we completed assessments with the person living with dementia, especially during the MMSE, as they were confronted with the degree of impairment their loved one had.

Another example of rejection, in a more dramatic case, was an aggressive one: A researcher called the trial participants to inform them of which treatment condition they had been randomised to. After telling them they had been assigned to usual care, the researcher was scolded and yelled at because the participant expected to receive the music intervention.

As researchers and members of a large international trial team, we were professionally prepared for such situations. However, this did not prevent us from experiencing emotional reactions both during and after these encounters. The rejections created feelings of uncertainty and doubt within us, and we sometimes felt powerless and defeated. These feelings, in turn, could lead to self-criticism and disappointment in ourselves. They drained our energy and created insecurity and demotivation. At times, we also perceived these rejections as personal failures. What helped us manage these rejections, especially those involving more hostile reactions, was the concept of putting on a professional mask—or a shield—that created a distinction between us as private individuals and as professional researchers. Equally essential was the support from colleagues and having regular opportunities to share and discuss our experiences. "Regular opportunities" meant having scheduled meetings where we could raise any issues, as well as an open culture of communication where it was acceptable to contact each other to discuss or debrief throughout the process.

Theme 3: Empathic disruption

The third theme is *empathic disruption.* Here, empathy refers to an intersubjective mindset in the researchers: intuitively, we sought to understand the other persons' (trial participants, stakeholders, etc.) situations and feelings and respond accordingly. We attuned both intuitively and consciously to the other person to build rapport, gain trust, and communicate understanding, just as we are trained to do as music therapists. In a way, we immersed ourselves in the other person's situations at all stages of the clinical trial research process, from recruitment to screening, assessments, and interventions. It seems we believed that this was a prerequisite for conducting research and completing the trial in an ethically sound manner. Our "ideal" disruption was an empathic one.

An example of what we mean can be drawn from the interventions. In our trial, the researcher trained participants randomised to the music intervention to use music in their daily lives for well-being and health benefits. The training was tailored to the individual needs of the participating dyad. This required continuous attuning to what the dyads wanted or needed while balancing between providing empathic support for the status quo and challenging or encouraging them to try something new. Some dyads could get "stuck" in rigid interaction patterns, having fixed ideas about how certain situations should be resolved. It was not always easy for the researcher, who was the trainer on the other side of the screen, to suggest different and new ways of doing things to the participant dyads. For the researcher, encouraging or almost being pushy felt like taking a risk—especially when the participants' everyday lives were stressful and demanding. As we have mentioned before, the participants in the trial lived in vulnerable life situations and often expressed

their vulnerability. The professional experience that things could go well and essentially benefit the dyad, along with witnessing positive changes in trial participants, was an emphatic reminder to keep going.

However, because of their vulnerable situations, there were times when we found ourselves not only attuning to their situation and emotions, but stepping into a condition or mindset that we have termed an *armour of empathy*. This was an attempt to protect the participants from their difficult and demanding situations, and to avoid disrupting them more than they could handle. We adopted this armour because of our foundational wish to protect the participants and our ethical mandate to "do no harm". Although seemingly a positive concept, stepping into an armour of empathy could also lead to over-interpreting the participant's feelings and perhaps assuming things on their behalf that might or might not be correct. Our fear of causing harm—of disrupting too much—could make us step back, for instance, not asking them to participate for the third time or not expecting them to engage in activities as much as planned.

Theme 4: Disruptive dissonance

The fourth theme refers to phenomena that are complex and contain contradictions, creating dissonance and causing conflicting experiences within us—*a disruptive dissonance*. At an overall level, the trial exposed both hope and loss, resilience and disability. On an individual level, this created dissonance when researchers found themselves as messengers of loss or illness while wanting to be messengers of hope, meaning, and agency. One example from the assessments was meeting trial participants online for the first time for a baseline assessment. The assessor believed in the importance of conducting research and in the project as a whole. She also believed in the potential benefits for the trial participants, viewing the research project as a messenger of hope and a means to build resilience. However, some questions in the assessment were confronting and forced participants to evaluate difficult aspects of their lives. Completing a cognitive test highlighted the person with dementia's disability. The assessor endeavoured to create a safe and comfortable environment from the other side of the screen. Still, some participants became upset during or after the assessment, and as researchers, we had conflicting feelings about being the ones asking questions that focused on these difficult aspects of their lives to obtain the data the trial needed.

Another dissonance relates to accumulating experiences with disruptions and how they affected us, the researchers, in contrasting ways. With experience comes confidence, and both intervention trainers and assessors became more capable of tolerating disruptions over time: we built resilience. However, repeated experiences of disruptions could also be draining for the researcher. Negative rejections could make the researcher *less* resilient and lead to insecurity. For instance, following an assessment that was difficult for the participants, an assessor might approach the next assessment worrying that she would upset the participants, feeling bad about putting them through all the questions even before getting started.

Dealing with contradicting communication is another type of disruptive dissonance. For example, when we called someone, we often began with, "I'm sorry to disturb you. Is this a good time to talk?" Some people responded, "No, not really, I'm at the shop [or out for a walk or similar] but just go ahead". This created dissonance for the researchers, as we were given permission

to talk, yet simultaneously not. While this may seem minor, such dissonances require thoughtfulness—considering whether it is truly okay to proceed—and can be tiresome if they occur frequently (cf. accumulative experience).

Other examples that could create dissonance included situations where the person with dementia and their caregiver had different and conflicting needs, or when participants and researchers had very different perceptions of time. Another significant disruptive dissonance was the need to balance adhering to a structured research protocol with being open, flexible, and improvisational to meet the individual needs of the participants. This was a continuous balancing act throughout the trial.

DISCUSSION

In this study, we ask: *What types, characteristics, and/or qualities of disruptions can be experienced within a randomised controlled trial?* In a qualitative self-study, we explored eight researchers' lived experiences of disruptions during a randomised clinical trial. Based on the data analysis, we identified four types of researcher disruptions: *background noise, rejection, empathic disruption,* and *disruptive dissonance*. These themes point to different disruption qualities, involving cultural, relational, and emotional aspects, that affect the researchers in various ways. They also emphasise that disruptions can be ambiguous and influence each other. Therefore, navigating them is not always straightforward. This, in turn, suggests that disruptions are always situated and must be interpreted in context.

In our deepened understanding of disruption, the various disruptions seem to constantly intertwine, influencing how each is experienced. For example, the amount of background noise in the research process can make us more sensitive to rejections, perhaps even making us misinterpret responses as rejections. In turn, encountering several rejections can reinforce our armour of empathy because we anticipate things to be difficult and potentially upsetting. Two background noise disruptions, such as dementia and online interaction, can also interact and escalate the overall level of noise.

An aspect that has become even clearer to us through this study, more so than at the outset, is the ambiguity of the phenomenon of disruption. This ambiguity carries a great potential for misinterpretation. We have learned that, as a cultural phenomenon, disruption may be influenced by societal aspects and the culture of a country. For example, the "distance rule of politeness" in Norwegian culture (Rygg, 2017) resonates with our experiences and findings in this study. Throughout the trial, we were concerned about disrupting people and spent a great deal of time discussing the balance between disrupting enough and disrupting too much. However, all the researchers in this study, as well as most trial participants, potential participants, and stakeholders we encountered during the trial, were Norwegian, with very few from non-Western cultures. Therefore, we cannot assume that our findings are applicable in other cultural contexts. How disruption is interpreted across different cultures and countries is a relevant area for further exploration, especially given the emphasis on international collaboration and a global approach to research and innovation in policies and programs, such as those from the EU (see European Commission, Directorate-General for Research and Innovation, 2021). Collaboration across countries can create

disruptions, such as background noise due to language barriers. However, understandings of disruptions may differ between cultures, and cultural exchange can also potentially lead to an expanded interpretative field of the phenomenon.

Disruption is, in our understanding, also a relational phenomenon. As mentioned earlier, developing interpersonal relationships is seen as essential in qualitative research (Eide & Kahn, 2008). It seems this is also the case in a large quantitative clinical trial like ours. Disrupting people to get them to participate in a trial, try out an intervention, share their experiences, and provide detailed information about their health and life circumstances—all of this requires a certain amount of trust. Kerasidou (2017) makes a distinction between trust and reliance, and claims that both are necessary in research. Reliance can be strengthened through laws, principles, or guidelines regulating the research process. Trust, however, "is an emotive relationship of dependency associated with risk and vulnerability" and "greatly depends on the character of both the trustor and the trustee" (Kerasidou, 2017, p. 48). Characteristics or virtues associated with a good researcher include, among others, courage, respectfulness, responsibility, humility, and prudence.

Kerasidou (2017) suggests that institutions should foster and encourage ethical conduct through educational programs, dedicated ethics teams, and engagement with stakeholders to promote the social value of research. We argue that trust also requires a closer interpersonal relationship, which Kerasidou (2017) refers to as personal trust. Based on our findings, we believe that an empathic approach with relational skills is essential in building trust relationships. For us, empathic disruption seemed to be a prerequisite for implementing the trial in an ethically responsible manner. Essentially, this meant combining our skills as music therapists with the role of researchers. As music therapists, we are trained to attune to the other person and sensitively adjust to their emotions and expressions in the interaction (Trondalen, 2016). This relational sensitivity requires improvisational skills—skills that are also essential in flexibly handling and containing contradictions and disruptive dissonances that may occur during a trial. Disruptions, in this sense, call for a sensitive and improvisational approach where balancing dissonances and a spectrum of emotions during the process is required. As such, we argue that relational and improvisational skills are essential researcher skills in all research involving interactions between human beings, including quantitative clinical trials.

However, one could ask whether our background as humanistic-oriented music therapists (Ruud, 2010), emphasising a relational perspective (Trondalen, 2016), and our experience in qualitative research have led us to overemphasise relational and empathic aspects of disruption. This may have reinforced our armour of empathy, making us overly protective of others' feelings and perhaps underestimating their capacity to cope with disruptions. Our Norwegian cultural "distance rule of politeness" (Rygg, 2017) may have further reinforced this armour. While protecting vulnerable participants is important and sometimes necessary, we should also consider whether our armour of empathy sometimes leads us to have too low expectations of what can be achieved in the interaction. Perhaps this armour occasionally gets in our way. Therefore, we should also ask: Do we expect rejection and, by doing so, restrict the interaction when we could instead open up to new possibilities? If we let our guard down, could we be positively surprised?

We recall discussing in the focus group interviews whether—and when—our armour of empathy might not align with the trial participants' needs. Sometimes, participants needed the opposite of our

protective stance. Instead, they wanted us to step up, engage, motivate, and push them to explore new activities that could potentially benefit them. The trial project leader recalls a participant approaching her and suggesting that we should not be so afraid of disrupting. At times, our armour of empathy was perhaps more about shielding ourselves from the discomfort of being agents of disruption rather than protecting the participants.

Being overly careful, too considerate, and assuming things on others' behalf without disrupting can hinder the progress of collaboration. As human beings, we need to be challenged to feel that we are moving forward. Stensæth (2017), in her perspectives on responsiveness, claims that it is essential for us all to experience risks and new learning in our interactions with the world and each other. Without challenges, we may become stagnant and lose interest, becoming less responsive. Disruption can be understood as a challenge in the interaction, and when balanced with trust and empathy, it can be a productive force that leads to innovation, growth, or new solutions (see also Boston-Fleishhauer, 2015; Christensen et al., 2015; Ganguly & Kumar, 2022; Kirp, 2022). In this sense, to disrupt can be understood as a way to care and show respect.

Perhaps an expanded understanding of research ethics is needed to help researchers navigate disruptions, an understanding that goes beyond conventional principles and guidelines related to aspects such as the protection of rights, anonymity, minimising harm, and risk-benefit assessment (Muthuswamy, 2013; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Such principles are, of course, important, but they are not the only relevant ethical considerations. Rather than simply "aiming to do no harm through research, perhaps we need to consider the importance of disturbing systems in order to improve them" (Brandenburg & Gervasoni, 2012, p. 189). Could it be that we as researchers—but also as therapists, and even as human beings—have an ethical mandate to disrupt, to be agents of disruptions? Can disruption be viewed as an ethical demand (Løgstrup, 1997)? Although not without the risk of being rejected, providing disruption can open fields of possibilities, discover resources, and afford hope in difficult life circumstances. Such an understanding of disruption is far from our initial caution to minimise disturbances, viewing them as potential burdens (see also Kusch & Potthoff, 2019). To fully understand these ethical considerations, a study articulating reflections from research participants would be valuable to complement the researchers' understanding provided in this study. It is, after all, the participants who experience the disruption as either a positive change, a burden, or something else.

At the same time, one should recognise that we as researchers are affected by these disruptions, both professionally and personally. Disruption has emotional aspect, not only for the research participants, but also for the researchers when working with research participants and in experiencing it first-hand. Encountering disruptions and being an agent of disruption may be vitalising and can be experienced as meaningful. However, we found that it can also be burdensome for the researcher. It can negatively affect researcher's self-esteem, motivation, and energy levels. One important aspect that helped us deal with difficult disruptions and emotional reactions was support from colleagues and regular opportunities to share and discuss experiences of disruption. This facilitated learning experiences rather than negative spirals of self-critique. This study itself was also in some ways part of the sharing and discussion. In our experience, naming the phenomenon and its different qualities and aspects contributed to an increased tolerance and resilience in facing

disruptions. Interestingly, this potential to help people cope with challenging experiences and make sense of their roles and reactions is also highlighted as an advantage of collective autoethnography (Karalis Noel et al., 2023).

We therefore view a supportive community of colleagues as vital for researcher's well-being. This aligns with Garrels et al. (2022), who call for research institutions to establish an atmosphere that allows researchers to communicate feelings of uncertainty and discomfort resulting from encounters with vulnerable research participants. It is also supported by other studies showing that post-graduate researcher's well-being is positively affected by personal and professional relationships, and that social support resilience may be a protective mental health factor (Crook et al., 2021; Gooding et al., 2023). We found that administrative or practical facilitation, such as scheduled and regular team meetings, can aid in creating a supportive community. However, trusting relationships may also be necessary for each researcher to show their vulnerability and share their experiences. Empathic disruption, relational sensitivity, and improvisational skills are therefore not only relevant in encounters with trial participants but also in research collaboration and team management.

When looking back on this study's research process, we acknowledge that keeping the methodology open and explorative might have weakened the study's credibility and reliability. Such an exploratory approach can be messy and difficult for the reader to follow. Selecting an established methodology with well-defined methods and analytical procedures could have been easier for us to use and for others to verify. At the same time, an explorative approach can be a strength in that it allows one to remain open and creative. Our experience in this study has been that the explorative and open approach, although demanding, has helped us to uphold our own reflexivity. As such, it has led us to reflect critically not only on *what* the data reveals but also on *who* sees *what* and *when*, and *how* we see it. Searching for meaningful methodologies along the way has been a learning experience. For us, the open and explorative approach has been a way to maintain a responsive mindset throughout the process, which was important to us.

In retrospect, we also recognise the significant impact that COVID-19 had on us and this study. As noted in the literature, the pandemic created disruptions for many trials, trial participants, and researchers (Bierer et al., 2020; Sathian et al., 2020). The pandemic likely made it even more challenging for us, as Norwegian humanistic-oriented music therapy researchers new to large clinical trials, to deal with the other disruptions present in clinical trials. This might have created a congestion of disruptions for us and within us, especially in the beginning, which could explain the need we felt to engage in the present study.

The findings in this study represent only our experiences and perspectives. Our study and its reflections provide just one part of a bigger picture. We have explored disruptions from one side of the table, the researcher side, and from a small group of eight researchers. However, there is always more than one side to a table. A disruption goes both, or many, ways; the disrupted and the disruptor interact and affect each other, and disruptions can affect responsiveness. We acknowledge that disruption in clinical trials may be experienced differently by others—other researchers, researchers in fields or traditions different from our own, trial participants, stakeholders, or administrative staff. Disruption could be explored further from all these perspectives. However, we hope our findings can

be helpful to others encountering disruptions by naming some aspects and qualities of this multifaceted phenomenon.

CONCLUSION

This study supports literature showing that disruption can be experienced as both positive and negative for those involved in clinical trials. Sometimes, it can be understood as a productive challenge that may lead to positive change, innovation, or growth. In this sense, disruption could be viewed as an ethical mandate to care for each other as human beings. Through our self-study exploration, we have come to understand disruption as a comprehensive and integral part of the research process, and that dealing with disruption is a necessary part of conducting research, especially when it involves people as participants. We have also learnt that boundaries regarding how much disruption is tolerable or desired can differ for everyone. We have increasingly become aware that disruption is a theme to be continuously mindful of in research trials. As researchers, we are constantly agents of disruption. As such, we must perform a continuous balancing act because the boundaries of how much disruption is desired and tolerated may differ for different people, at different times, and in different contexts and relationships. Knowing when and how to disrupt—and when not to—requires ongoing interpretation, relational sensitivity, and improvisational skills.

Furthermore, conducting this study has taught us that when there are people involved on both sides of the research table—both navigating the dialogical processes to engage in the interventions and data collection of a clinical trial—disruptions are owned or felt by both sides. As researchers, we may hope to be a positive disruption, one that transforms the lives of individuals for the better while also advancing the field under investigation. However, a disruptive intervention may not always be effective, and disruptions may also be experienced negatively by participants. The interventions may even cause adverse events. This is the nature of research. Being a researcher entails dealing with all such disruptions. Although being agents of disruption can be both joyful and educational, studies, including the present one, show that it can also be challenging, uncomfortable, and disheartening. Researchers may themselves be disrupted by unexpected events during the research process, either directly or indirectly through others' disruptions or experiences. By recognising this and by viewing disruption as a phenomenon that requires dialogue and support within the research team, we can develop both as researchers and as a team.

Contributors statement: Conceptualisation and methodology: KJ. Funding: KAS. Investigation: UJ. Analysis: KJ, KAS, TK, KS, RBE, SK, AM, HCWA. KJ and KAS drafted the initial manuscript. All authors contributed to interpreting data and findings, revising the manuscript and approving the final version for submission.

Conflict of interest: The authors have no conflicts of interest to declare.

Acknowledgements: We wish to acknowledge the international research team on the HOMESIDE trial (www.homesidestudy.eu) without which this study would not have been possible.

Funding: Centre for Research in Music and Health (CREMAH), Norwegian Academy of Music.

REFERENCES

Baker, F. A., Pac Soo, V., Bloska, J., Blauth, L., Bukowska, A. A., Flynn, L., Hsu, M. H., Janus, E., Johansson, K., Kvamme, T., Lautenschlager, N., Miller, H., Pool, J., Smrokowska-Reichmann, A., Stensæth, K., Teggelove, K., Warnke, S., Wosch, T., Odell-Miller, H., & Tamplin, J. (2023a). Home-based family caregiver-delivered music and reading interventions for people living with dementia (HOMESIDE trial): An international randomised controlled trial. *eClinicalMedicine*, 102224. https://doi.org/10.1016/j.eclinm.2023.102224

Baker, F. A., Blauth, L., Bloska, J., Bukowska, A. A., Flynn, L., Hsu, M. H., Janus, E., Johansson, K., Odell-Miller, H., Miller, H., Petrowitz, C., Pool, J., Stensæth, K., Tamplin, J., Teggelove, K., & Wosch, T. (2023b). Recruitment approaches and profiles of consenting family caregivers and people living with dementia: A recruitment study within a trial. *Contemporary Clinical Trials Communications*, *32*, 101079. https://doi.org/10.1016/j.conctc.2023.101079

Bierer, B. E., White, S. A., Barnes, J. M., & Gelinas, L. (2020). Ethical challenges in clinical research during the COVID-19 pandemic. *Journal of Bioethical Inquiry*, *17*(4), 717–722. https://doi.org/10.1007/s11673-020-10045-4

Boston-Fleischhauer, C. (2015). Disruptive innovation: Latest buzzword or new reality? *JONA: The Journal of Nursing Administration*, *45*(10), 469–470. https://doi.org/10.1097/NNA.0000000000000235

Brandenburg, R., & Gervasoni, A. (2012). Rattling the cage: Moving beyond ethical standards to ethical praxis in self-study research. *Studying Teacher Education, 8*(2), 183–191. https://doi.org/10.1080/17425964.2012.692991

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2022). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *International Journal of Transgender Health*, *24*(1), 1–6. https://doi.org/10.1080/26895269.2022.2129597

Brinkmann, S., & Kvale, S. (2015). *InterViews: Learning the craft of qualitative research interviewing* (3rd ed.). Sage.

Cambridge Advanced Learner's Dictionary & Thesaurus. (n.d.). Disruption. In *Cambridge English Dictionary online*. Retrieved October 1, 2024, from https://dictionary.cambridge.org/dictionary/english/disruption

Christenson, C. M., Raynor, M., & McDonald, R. (2015). What is disruptive innovation? *Harvard Business Review*, December 2015.

Coyle, J., Rogers, A., Copland, R., De Paoli, G., MacDonald, T. M., & Mackenzie, I. S. (2022). Learning from remote decentralised clinical trial experiences: A qualitative analysis of interviews with trial personnel, patient representatives, and other stakeholders. *British Journal of Clinical Pharmacology*, *88*(3), 1031–1042. https://doi.org/10.1111/bcp.15003

Crook, R., Gooding, P., Whittaker, C., Edge, D., Faichnie, C., Westwood, M., & Peters, S. (2021). Student, academic, and professional services staff perspectives of postgraduate researcher well-being and help-seeking: A mixed-methods co-designed investigation. *Studies in Graduate and Postdoctoral Education*, *12*(1), 113–130. https://doi.org/10.1108/SGPE-08-2020-0056

Eide, P., & Kahn, D. (2008). Ethical issues in the qualitative researcher-participant relationship. *Nursing Ethics*, *15*(2), 199–207. https://doi.org/10.1177/0969733007086018

European Commission, Directorate-General for Research and Innovation. (2021). Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee, and the Committee of the Regions on the global approach to research and innovation: Europe's strategy for international cooperation in a changing world. COM (2021) 252 final/2. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2021%3A252%3AFIN

Ganguly, A., & Kumar, C. (2022). Disruptive innovation in healthcare: A review and future research agendas. *International Journal of Innovation Management*, 26(1). https://doi.org/10.1142/S1363919622500025

Garrels, V., Skåland, B., & Schmid, E. (2022). Blurring boundaries: Balancing between distance and proximity in qualitative research studies with vulnerable participants. *International Journal of Qualitative Methods*, *21*. https://doi.org/10.1177/16094069221095655

Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic management of behavioral symptoms in dementia. *JAMA*, *308*(19), 2020–2029. https://doi.org/10.1001/jama.2012.36918

Gooding, P., Crook, R., Westwood, M., Faichnie, C., & Peters, S. (2023). Social support resilience as a protective mental health factor in postgraduate researchers' experiences: A longitudinal analysis. *Studies in Graduate and Postdoctoral Education*, ahead-of-print. https://doi.org/10.1108/SGPE-04-2022-0032

Hamilton, M. L., & Pinnegar, S. (1998). Conclusion: The value and promise of self-study. In M. L. Hamilton (Ed.), *Reconceptualizing teaching practice: Self-study in teacher education* (pp. 264–277). Falmer.

Hunt, A. M. (2016). First-person research. In B. Wheeler & K. M. Murphy (Eds.), *Music therapy research* (3rd ed.). Barcelona Publishers.

Karalis Noel, T., Minematsu, A., & Bosca, N. (2023). Collective autoethnography as a transformative narrative methodology. *International Journal of Qualitative Methods*, *22*. https://doi.org/10.1177/16094069231203944

Kerasidou, A. (2017). Trust me, I'm a researcher!: The role of trust in biomedical research. *Medicine, Health Care and Philosophy*, *20*, 43–50. https://doi.org/10.1007/s11019-016-9721-6

Kirp, D. L. (2022). *Disrupting disruption: The steady work of transforming schools*. Oxford University Press. https://doi.org/10.1093/oso/9780197651995.001.0001

Kitchen, J., Berry, A., Bullock, S. M., Crowe, M. T., Guðjónsdóttir, H., & Thomas, L. (Eds.). (2020). *International handbook of self-study of teaching and teacher education practices* (2nd ed.). Springer.

Krueger, R. A., & Casey, M. A. (2015). *Focus groups: A practical guide for applied research* (5th ed.). SAGE Publications.

Kusch, K., & Potthoff, D. (2019). Eliminating 'disruption' for patients in clinical trials. *Applied Clinical Trials*, *28*(10), 17–19.

Lalanza, S., Peña, C., Bezos, C., et al. (2023). Patient and healthcare professional insights of home- and remote-based clinical assessment: A qualitative study from Spain and Brazil to determine implications for clinical trials and current practice. *Advances in Therapy*, *40*, 1670–1685. https://doi.org/10.1007/s12325-023-02441-0

Løgstrup, K. E. (1997). *The ethical demand*. University of Notre Dame Press.

Merriam-Webster. (n.d.). Disruption. In *Merriam-Webster.com dictionary*. Retrieved October 1, 2024, from https://www.merriam-webster.com/dictionary/disruption

Morgan, D. L. (1998). *The focus group guidebook*. In the Focus Group Kit Series. SAGE Publications. https://doi.org/10.4135/9781483328164
Muthuswamy, V. (2013). Ethical issues in clinical research. *Perspectives in Clinical Research*, *4*(1), 9–13. https://doi.org/10.4103/2229-3485.106369
National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. U.S. Department of Health and Human Services. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html
Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2022). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 1–11. https://doi.org/10.1080/0142159X.2022.2057287
Park, M., Leahey, E., & Funk, R. J. (2023). Papers and patents are becoming less disruptive over time. *Nature*, *613*, 138–144. https://doi.org/10.1038/s41586-022-05543-x
Randell, R. L., Singler, L., Cunningham, A., Schanberg, L. E., Cohen-Wolkowiez, M., Hornik, C. P., Balevic, S. J., & the CARRA Registry Investigators. (2021). Delivering clinical trials at home: Protocol, design and implementation of a direct-to-family pediatric lupus trial. *Lupus Science & Medicine*, *8*(1), e000494. https://doi.org/10.1136/lupus-2021-000494
Ruud, E. (2010). *Music therapy: A perspective from the humanities*. Barcelona Publishers.
Rygg, K. (2017). 'Typically Norwegian to be impolite.' Impoliteness according to whom? *FLEKS - Scandinavian Journal of Intercultural Theory and Practice*, *4*(1). https://doi.org/10.7577/fleks.2439
Sathian, B., Asim, M., Banerjee, I., Pizarro, A. B., Roy, B., van Teijlingen, E. R., do Nascimento, I. J. B., & Alhamad, H. K. (2020). Impact of COVID-19 on clinical trials and clinical research: A systematic review. *Nepal Journal of Epidemiology*, *10*(3), 878–887. https://doi.org/10.3126/nje.v10i3.31622
Stensæth, K. (2017). *Responsiveness in music therapy improvisation: A perspective inspired by Mikhail Bakhtin*. Barcelona Publishers.
Trondalen, G. (2016). *Relational music therapy: An intersubjective perspective*. Barcelona Publishers.
van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. State University of New York Press.
World Health Organization. (2023, March 15). Dementia. *World Health Organization*. https://www.who.int/news-room/fact-sheets/detail/dementia/?gclid=EAIaIQobChMIiLiHtenKgQMVLVSRBR17ZQROEAAYASAAEgIsPPD_BwE
Zhao, N., Zhang, X., Noah, J. A., Tiede, M., & Hirsch, J. (2023). Separable processes for live "in-person" and live "Zoom-like" faces. *Imaging Neuroscience*. https://doi.org/10.1162/imag_a_00027

Ελληνική περίληψη | Greek abstract

Θόρυβος, αμφιβολία, ενσυναίσθηση ή έκπληξη; Μια ποιοτική συλλογική αυτομελέτη που εξετάζει το φαινόμενο της διατάραξης στις κλινικές δοκιμές

Kjersti Johansson | Tone S. Kvamme | Kristi Stedje | Runa Bosnes Engen | Unni Tanum Johns | Solgunn E. Knardal | Anette D. Moltubak | Hanne Cecilie Webb Aamodt | Karette Annie Stensæth

ΠΕΡΙΛΗΨΗ

Οι διαταράξεις αποτελούν αναπόσπαστο μέρος των κλινικών δοκιμών, συχνά αντιπροσωπεύοντας ηθικές προκλήσεις. Ως ερευνητές, είμαστε φορείς διατάραξης: παρεμβαίνουμε στις ζωές των συμμετεχόντων μέσω της εφαρμογής παρεμβάσεων και της συλλογής δεδομένων, συνεργαζόμαστε με ενδιαφερόμενους και ζητάμε την υποστήριξη συναδέλφων. Πώς επηρεάζουν αυτές οι διαταράξεις τους ίδιους τους ερευνητές; Σε αυτή τη μελέτη, διερευνούμε τις διαταράξεις από την οπτική γωνία του ερευνητή, μέσα από μια ποιοτική αυτομελέτη των εμπειριών μας, καθώς εργαζόμαστε από κοινού σε μια διεθνή τυχαιοποιημένη ελεγχόμενη δοκιμή. Τα δεδομένα περιλαμβάνουν ποιοτικές συνεντεύξεις με εμάς, την ερευνητική ομάδα μουσικοθεραπείας από το νορβηγικό συνεργαζόμενο ίδρυμα της δοκιμής. Οι συνεντεύξεις αναλύθηκαν μέσω μιας συνεργατικής αναστοχαστικής θεματικής ανάλυσης. Εντοπίστηκαν τέσσερα θέματα, που αντιπροσωπεύουν διαφορετικούς τύπους διατάραξης και ποιότητες στις εμπειρίες μας: *υπόκωφος θόρυβος*, *απόρριψη*, *ενσυναίσθητη διατάραξη* και *διασπαστική παραφωνία*. Τα θέματα αυτά μοιράζονται τα χαρακτηριστικά ότι είναι σχεσιακά, ενίοτε διφορούμενα, και επηρεάζουν το ένα το άλλο, απαιτώντας ερμηνεία ανάλογα με το πλαίσιο. Αυτή η πολυπλοκότητα τα καθιστά δύσκολα στον ορισμό και τη διαχείρισή τους. Υποστηρίζουμε ότι ο συνεχής προβληματισμός σχετικά με τις διάφορες διαταράξεις και η

διαπραγμάτευση των ορίων τους είναι ζωτικής σημασίας για τη διασφάλιση υψηλών δεοντολογικών ερευνητικών προτύπων και για την υποστήριξη της αυτοφροντίδας των ερευνητών.

ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

διατάραξη, κλινικές δοκιμές, αυτομελέτη, ηθικά διλήμματα, αυτοφροντίδα των ερευνητών