Ethics and data collection in arts-based inquiry:

Artist-researcher embedded in medical education

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Introduction

This paper explores ethical issues arising from a setting in which an individual artist-researcher conducts a study in a medical school, operating both as a principal investigator and generator of arts-based outcomes. I discuss these issues in the light of my current postdoctoral project and its data collection phase at the Faculty of Medicine and Dentistry in the University of Alberta in 2011. At the focus of this project are the various representations of the body embedded in the preclinical curriculum.

In this text an *artist-researcher* refers to an artist who is engaged with a doctoral or postdoctoral study within academia. I do not then discuss the kind of (background) research that artists commonly do for their work, or artists that engage with medical themes separate from academic research.

Interestingly, the discussion about various research approaches and terminology employed in such processes seems geographically clustered (Mäkelä et al. 2011). Relating to the European context, in which I am trained, my inquiry manifests in sub-

fields of artistic research, namely, in *research through art* (Freyling 1993) and *research-based practice* (Tikka 2008:18). In North American discourse, however, my work can be associated with the field of *arts-based (health) research.*

The ethical issues related to qualitative research practice can be roughly divided into procedural ethics, usually related to an ethics committee approval, and the everyday ethical issues arising from doing research (Guillemin and Gillam 2004:263). In this text I touch upon both these ethical dimensions, beginning with the dialogue between the ethics approval process and artistic decisions involved in arts-based inquiry. This paper concerns the data collection phase and the ethical issues that arise within. I consider here the various ways the ethics approval process has directed my decision-making, and reciprocally, the ways my artistic agenda influences the direction of the research study.

Study description

As a part of my postdoctoral research project (2011-2013) I have conducted a data collection phase at the Faculty of Medicine and Dentistry in the University of Alberta. The fellowship was located in the faculty's Arts and Humanities in Health and Medicine program, and ran for a three-month period from September to November in 2011. The arts-based methods used involve video, photography, performance and visual arts. The aim of the project was for the form and function of these methods to blend: performative text can be seen a space that can be simultaneously asserted for inquiry and expression (Finley 2003:287).

Data for the study under consideration was collected through participant observation and interviews. For the first two months I was immersed in the medical curriculum, following various classes, such as problem-based learning and community-based experiences, offered for the preclinical students as well as the online study material involved. I additionally conducted several informal discussions with the faculty members. Some of these discussions are audiotaped and some are recorded with speedwriting. During the third month I conducted 13 semi-structured interviews involving seven preclinical students and five of their physician preceptors. Each interview lasted approximately one hour and was recorded with two video cameras and an audiorecorder.

Artist-researcher: multiple positionings

Arts-based methods in health research often require collaboration between researchers and artists (Cox et al. 2010:119). In these situations the artist is typically employed after the data collection to render an artistic impression of the data. However, this paper involves a setting in which the same person operates both as an artist and a researcher, and generates and disseminates much of the data through artistic means. This has the benefit that the artist-researcher has conducted the data collection herself, and has thus been deeply interwoven into the study context. Furthermore, the whole study is initiated by her, thus merging the art and research components from the beginning. In this perspective one literally manifests the arts-*based* quality. The dual position as an artist-researcher, however, can create various conflicts of interest: even though I aim to map the various representations of the body in preclinical curriculum, I am also aiming to create artworks on their own right, without compromising their artistic qualities. Furthermore, in the practice of arts-based inquiry, maintaining the

reciprocal trust and respect with the participants and enjoying artistic freedom might appear as two competing values.

Artist-researcher's data collection involves artistic choices. In the process I do not first appear as a 'conventional' researcher and then an artist, but I make artistic decisions *during* collecting data as well. Every decision has, in fact, artistic consequences, and I am continuously aware that the data will reemerge in the artworks in various ways. In fact, in my view a (visual) data collection always involves partly composing it, since the viewpoint, light, frame and montage, both metaphorically and literally,are directed by the researcher. Furthermore, being trained in different cinematic techniques, and aware how these color any moving image representation (Dijck van 2005:26) I might view some of the central concepts of qualitative research, such as *authenticity* differently. In my project it first and foremost means that I as an artist-researcher need to be authentic by monitoring my motivations and methods. Visual authenticity of the data, however, is in many ways in the eye of the beholder.

The dispersed loyalty, caused by the dual position as an artist-research, can raise ethical issues during the research project. In certain ways I have delivered a part of my autonomy as an artist due to my positioning. For starters, as I am enjoying a project funding from the Academy of Finland, I have promised to execute a particular research plan and will be held responsible for that. Secondly, by being invited as a postdoctoral fellow to the University of Alberta, and the ethics approval procedure, positions me in a variation of a client-like relationship, in which I am producing a 'portrait' of the medical school. That is, the individual participants are not the only

subjects for portrayal: the institution within which they operate will be part of that portrait as well.

Developing the inquiry approach: working with human ethics guidelines

Before arriving in Canada, I had not been aware of cultural differences regarding the ethical review of arts-based inquiry in health settings. When I began my fellowship, I naively thought I could start filming in the medical school as long as nobody was identifiable in the images. This was due to coming from a casual Dutch context in which I had filmed earlier within (health) educational situations without an ethics approval. However, I soon learned that in Canada ethics approval was needed. Following my introduction to the undergraduate medical program at the University of Alberta, I had already begun to refine my proposed inquiry project taking into consideration what I had learned and experienced about the pre-clinical curriculum. Then, when I embarked on preparing the ethics application for my study with Dr. Pamela Brett-MacLean (as my postdoctoral supervisor), I began to reconsider my research project again, with a view toward ensuring a successful ethics protocol within a short period of time. I considered what was possible: 1) given need to abide to guiding ethical principles such as ensuring free and informed consent, respect for confidentiality, and minimizing potential harm (as outlined in the Health Research Ethics Board's protocol); and 2) also recognizing the time constraints I was working with. Reciprocally, my artistic agenda influenced the direction of my research inquiry and my decision-making throughout this process.

At first glance, the ethics protocol would seem counterproductive for the creative process: the conditions for recording the interviews and participant interactions need

to be determined beforehand, and restrict the degree of responsive improvisation in the midst of the inquiry. However, artists commonly work with constraints, for example when they work on a commission, or are bound to stipulations attached to the use of funding awards. Artists thus learn to navigate these various requirements.

As an artist-researcher I began with an idea, and then followed a process of deduction and speculation in trying to navigate the ethics protocol. In my experience the protocol appeared as a ritual, in which the appreciation of certain rhetoric, the repetitious structure and confirmations form a precious oath, an earned license which legally-emotionally ties me with the institution, the participants and the data involved. As a researcher, I understood the ethics protocol, at least within the Canadian context, as a necessary step in obtaining approval for my project. As an artist, being used to employ materials from various sources, I viewed the ethics procedure as a part of the total experience of the medical school and therefore my study material.

On October 31st, 2011, the University of Alberta Research Ethics Board approved the study we submitted, entitled "Representations of the body in medical education: An arts-based inquiry" (Pro00026304). Some descriptive content from the Letter of Information provided to prospective participants is excerpted below:

> ***Purpose of the Project:***
>
> This project aims to explore the educational pathways that lead to learning the role of the physician and reading, or understanding the patient in relation to their body (e.g., signs, symptoms), according to the strategies offered in the medical curriculum. It aims to illuminate the kinds of body representations embedded in pre-clinical medical education, and how these representations parallel how

faculty preceptors and students experience and describe themselves as physicians or physicians in training. Instead of analyzing sociological or psychological aspects and accounts of the doctor's role, this project will use arts-based methods to explore a variety of texts employed in undergraduate medical education. The project raises awareness of the multiple, complex meanings associated with the process of becoming a doctor and caring for patients, and subsequently will invite others to consider their own body and health conceptions, and expectations of medicine. This project will also give participants an opportunity to reflect upon their profession, and thus gain new insights into their careers, professional commitments, and ongoing identity formation.

Study Procedures:

 Individual interviews lasting from 45-60 minutes will be held… (with faculty preceptors, and first and second year medical students). Dr. Kaisu Koski will ask a series of open-ended questions that focus on the participant's experience of medical education, and representations regarding the body as they have experienced in the undergraduate curriculum. In addition, faculty preceptor volunteers will be invited to choose a short passage from the "Hippocratic Oath" that resonates strongly for them; student volunteers will be asked to select a short passage from the "Student Pledge of Conduct" which marks their transition from their pre-clinical education to the clinical component of their education. They will be asked to transcribe these written passages in their own handwriting. In addition, participants will also be asked to illustrate how they visualize the body in relation to "medicine" (e.g., becoming a doctor, patient care, or anatomy - whatever comes to mind) by drawing an aspect of the body, or full figure drawing.

….With permission of the participant, the interview will be video and audio-recorded. Participants may decline to be video-recorded. At a minimum, however, participants must agree to be audio-recorded. To protect the identity of participants, and also with a view toward to realizing various aesthetic aspects of the project, only the arms and hands of participants will be video-recorded. Only these images will be featured in film segments included in the arts-based, interpretive products that result from this inquiry. Also, again with the permission of the participants, the anonymous writing samples and drawings will be collected as empirical material informing this arts-based inquiry. These materials may also be used in artworks and publications that result from this arts-based inquiry.

Instead of recording the interviews as a mere memory aid, or to be re-enacted by performers, I wished to employ the actual audiovisual material recorded of the participants in the arts-based outcomes of the study. A lot of time was spent in preparing the image to be aesthetically and ethically appropriate.

The study I developed in the end was not what I originally intended. However, I came to realize that individual interviews provided a means of 'isolating' research participants, thus obviating the need to invest time in obtaining informed consent from others who might be included in visual images collected in group settings. In addition, I had learned that a study design that included collecting identifiable visual information, i.e. faces of the participants, would likely take several months to obtain ethical approval (given the need for clarifications, and revisions that would likely be requested by the Research Ethics Board). As I only had limited time to conduct the

study, I was driven to think of ways I could collect visual material that would be representative of the individual participants, recognizing them in terms of their individuality, but not in a way that would not be identifiable. I chose to work with the visual images of the participants' arms and hands.

> (Formulated in the ethics application:) Participants will be informed
> that their face and body will be obscured following the interview, and that only
> their arms and hands will appear in film segments that may appear in any arts-
> based, interpretive product that may result from this inquiry.

As outlined above, the semi-structured interviews I conducted with the medical students and their faculty preceptors were organized in three main parts. First, I asked each of the research participants a series of questions regarding their experience of teaching and/ or learning in medical education. Secondly, the participants were invited to complete a drawing and handwriting task. In addition, they were invited to participate in an optional, guided hand improvisation. Although the research participants were aware of different aspects of the interview, I struggled with the extent to which I would share specific details about different aspects of the study. Obscuring different aspects of a research study in order to encourage participation clearly presents ethical dilemmas (Karnieli-Miller 2009:282), still there are reasons why one might consider this. When one aims for an authentic rather than a practiced or rehearsed (even mentally rehearsed) response, it is helpful sometimes to describe the task in general terms. In addition, overemphasizing some of the tasks I invited the participants to complete might have served to alienate them. For example, many

people think about drawing as requiring artistic skill and some of the participants might have decided not to complete this task if they felt that this was my expectation.[1]

Even though the actual interview forms the core of the research data, for an artist-researcher who works with film, and as other researchers know, often the most interesting information is shared just before or after what is planned as the "formal interview." In this inquiry, I intentionally recorded my entire interaction with participants, right up until each participant left the room. I am not sure the participants were fully aware of this, although most were likely aware at some level. I announced that I had begun to audio and video-record the session after each participant read the letter of information, and signed the study consent form. The recording equipment remained on throughout our time together. On their own initiative, the participants often continued sharing personal stories, which were sometimes emotional. Indeed, with a few participants, it felt more natural to end the interview with a hug instead of a handshake. I am not sure how they would have considered these dialogues in relation to the overall inquiry. My intention was not to deceive the interview participants at a point when they might forget the presence of the camera. My purpose was to record as much of our interaction as possible, within the context of learning about their experience of representations of the body in medical education. The participants' stories have helped to enhance and extend my understanding and I have not used any individual story as a focus for a particular interpretive artwork. Their

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[1] When a participant initially shied away from completing the drawing exercise (stating 'I'm not an artist'), I encouraged them to just try the exercise, reassuring them I wasn't concerned about the level of artistry they might display, but rather was interested in the content of their visual representations.

stories are included among all the material I have compiled, on the basis of which I am creating a series of interpretive, abstracted artworks.

Informed consent, freely obtained, is foundational to the protection of research participants. This implies a responsibility to meaningfully and fully explain what the research is about (as far as is reasonably possible) and how it will be used or disseminated. In arts-based inquiry, however, it is impossible to share specific details regarding the outcomes of the study. As the process of collecting data merged with developing artistic forms, it was not possible to outline with any certainty what the completed artwork(s) might be like; indeed, participants may often be surprised by how their input appears within an artwork. The question here remains: how can one provide informed consent for outcomes that the artist-researcher cannot envision at the outset of the study?

Chalfen (2011) has suggested introducing a progressive or sequential approach to obtaining informed consent, in which participants are asked to agree to continue their participation at different points of a research project, and agree to different use of their materials, as this may evolve over time. In my project, each participant was told they could approach me during the week following their interview to listen to or view the audio and video-recorded material I had collected. At this point they could elect to withdraw completely from the study, or indicate which aspects of the data they wished to have deleted. As it occurred, none of the participants wanted to review their video-recordings. Only one participant asked to listen to the audio-recording I made of our interview. None of the participants wished to withdraw from the project.

At this point, it is not possible for any of the research participants to withdraw from the study (this was specifically outlined in their letter of consent). After viewing sketch images of the artworks in April 2012 they could decide whether they would like to be credited by name in relation to the exhibit of finished artworks based on this study and 12 participants wished to be credited with their full names with only one participant wishing to remain anonymous. In this way, protection of the artist-researcher and integrity of the arts-based inquiry approach is ensured. An artist-researcher cannot afford to work on an artwork for a half a year only to hear that a participant wishes to withdraw from the project. In this particular study, it would be impossible to do so, given the mélange of images and audio that are being constituted in the created artworks.

Control of research process; photo-improvisation

As an autonomous artist (which is a role I also sometimes assume) I control the various aspects of my work, including working with performers. One can ask the performers to do nearly anything, including embarrassing or emotionally distressing tasks respecting that they are professionally trained and paid to do so. As an artist-researcher, I could not expect to direct my research participants' input, or require them to execute certain actions. However, this does not mean that I would not compose the interview in many ways. I carefully considered all of the visual aspects within the interview setting, including the décor, props and camera angle. I directed the viewpoint, lighting, framing and montage, both metaphorically and literally. I spent weeks considering the "scene," spending time ensuring the setting and resulting images would be aesthetically and ethically appropriate. Other researchers may well

reflect on the extent to which they orchestrate their interactions with participants; I do so intentionally – with the intention of creating a research-based artistic outcome.

At the conclusion of the interview, I invited the participants to contribute to an improvisational hand photo-shoot. I invited them to represent different aspects of the human body (organs, knee bones, etc.). Some of the hand positions I had prepared beforehand; alternatively, I guided participants in achieving a self-chosen position. This semi-directional exercise was ethically interesting. I worried that my invitation to participate in this activity would potentially make participants feel uncomfortable, as they might felt that the purpose was to produce a photo that would satisfy my artistic goals. However, most participants were very enthusiastic about the challenge and were excited to see their freshly-made image on the camera screen at the end of our time together. While the photo shoot was not a participatory project in the sense that the participants would have held the camera themselves, it may be understood as a collaborative image-making process in which a particular task was completed by the research participants, which resulted in a series of artistically-rendered photographs (see Chalfen 2011: 188). In part, this aspect of the inquiry developed as a response to my concern that the interactive, dynamic, and emergent character of the inquiry might yield little usable data, at least from an artistic standpoint. This was, of course, not the case – but was a worry early on for me, in the midst of the inquiry.

[Excerpt from a hand photo-shoot with a participant (P)]
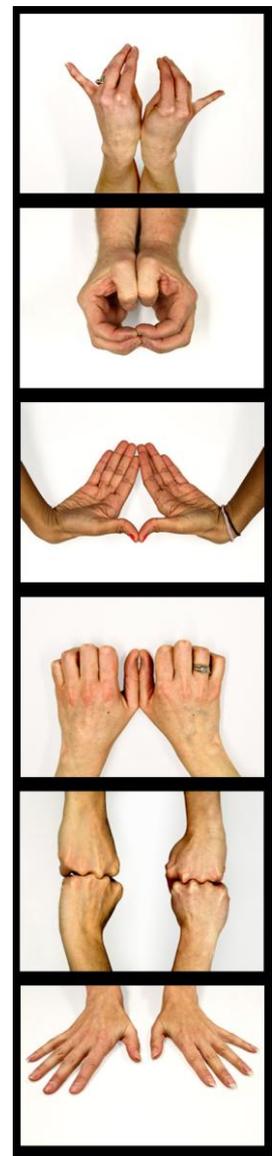
Image 1

Systems-based body 2012
© Kaisu Koski

KK: I've been asking people to form different organs with their hands. And as I now have this collection growing, I was having few options for you that you can choose from. One of the things I'm still missing is thyroid…

P: Thyroid!

KK: You know what I was thinking, it's like a butterfly.

P: Yes it is.

KK: You could do it like, cover the palms a little bit, and you could curve it also because it's kind of around the neck.

P: Yeah it kind of goes around like this.

KK: And you could do your pinky as the bottom wing of the..

P: Oh yeah it has this little kind of…

KK: And then if you could separate, like the fingers, because it's more like a..

P: It's been a long time since I looked at the picture of a thyroid

KK: It would be perfect, if you could bring your arms closer to each other, they would be like, you know, the tube. [click, click…] Can you make a bit more V like with your like main fingers? This is a pretty one!

P: Really? Okay.

KK: have a look at this! (showing camera screen).

P: Oh wow, you can see all my veins and it's good actually it's good that I'm so pale.

Sensitive topics

I developed my research inquiry in relation to concern for "minimizing harm." The contemporary approach to health research ethics, based on respect for human dignity, requires that researchers ensure that potential harms and benefits are not only balanced (with benefits outweighing harms) but that research participants are protected from, or compensated in relation to foreseeable harm or potential injury they may experience. Artists often wish to create work that emotionally engages an audience by highlighting difficult or controversial themes. The aim is usually not to shock the audience, but to consider difficult emotional topics as a fundamental part of human experience that should not and cannot be avoided in the course of life, but can sometimes begin to be grappled with via artistic media. Given the nature of my research question, my interview protocol did not involve broaching sensitive topics. In addition, participants were only encouraged to share what they were comfortable sharing.

However, one can never be sure where certain themes will lead even when attempting to prevent participant distress, when using qualitative, and particularly, arts-based methods. In addition, even though I did not ask the participants questions that might lead to sensitive topics, I have monitored whether "outcomes" of the project might potentially cause harm as I work with the data. I am aware that the participants' voices and hands may be identifiable by their colleagues and peers (within the medical school), and patients. I am also aware that their contributions might be misinterpreted within the context of specific artworks. Depending on the climate of the institution, their responses might also potentially conflict with the vision of the medical school, which will of course change over time.

Creative process: Reflexivity and authenticity

Art involves commonly a critique of things as they are, or a questioning of some kind. A medical school is a highly complex entity, which can hardly be grasped in three months. It would be arrogant for me to place a judgment on such a setting, following a preliminary exposure. What I feel I can aim for is conveying an understanding of what happens in the medical school: ways in which learning takes place, how the body is represented in the curriculum, and how students and their preceptors experience these representations. At the same time, as part of my creative process I continuously ask where am I located in the work (see Koski 2011), and what am I saying with it. I also experience a range of intellectual or emotional responses to all I have experienced, which contributes to my creative process and how I make meaning of the material I have collected. In this regard, I consider myself as one of the participants of the project, as the development of my own understanding is unveiled and questioned through the arts-based inquiry process (see Piirto 2002:442). The

studio-based material, produced after the data collection, is part of an externalization of my inner voice. It is relevant as a personal and emotional account on what I experienced during my observation – which will be made transparent in the project outcomes.

In arts-based inquiry, both the participant and researcher can be seen as storytellers: the participants tell their personal stories; in turn, the researcher recasts these stories into a "new" context (Karnieli-Miller 2009). My interpretation involves a dramatization of their stories. The new story is more than a collection of the participants' stories: I weave my story into the knit of the stories shared by the participants. As both an active participant and sometimes a silent observer, I have experienced some of the educational situations the participants describe in their interviews. As such, I am also juxtaposing my experience of the same situation with those of the students and preceptors in the work I am creating. My voice is relevant because it is simultaneously individual and universal: my preconceived ideas have been culturally cultivated and formed by the stories others have also shared. My understanding and interpretations may thus engage a wide range of individual responses.

Interview interpretations are always affected by what the researcher is able to hear, and thus represent a version of the truth (Hewitt 2007:1153). These interpretations, in turn, set the participants vulnerable. The interpretative dimension often gets amplified in arts-based inquiry: if an artist-researcher enters an interview with an artistic agenda, i.e. she has sketched a particular kind of artwork for which she collects material, she might attend to only to information and texts that fit her guiding framework. From

this perspective, I believe it is an essential part of an ethical research relationship that the researcher acknowledges her own bias and the need for reflexivity (Hewitt 2007:1155). Artists are commonly trained in questioning their motivations to work with particular topics and methods. In my viewpoint, the artist-researcher's openness to being changed, the transparency of her emotional and moral understanding are essential in arts-based inquiry.

With respect to the artistic process, and ethical relational aspects of the inquiry process, another complexity is found in relation to the artwork as an entity which the artist must remain loyal. Especially when an artwork begins to have enough substance for its form and/or content, it often seems to 'demand' particular kind of material or actions, and foremost authenticity, from the artist. In the creative process, I look at the work under construction and see or feel what it 'needs'. The artist-artwork relationship, literally manifests through the laws and techniques of a particular medium and skills and point of view of the artist, adding another dimension abstracted beyond the students and preceptors shared about their experience of the pre-clinical curriculum. The artwork-in-progress can thus be metaphorically seen as one of the participants of the study, which has its voice, and competes for the artist-researchers loyalty.

At the same time, I appreciated the time and contributions the participants freely gave to my study. I feel a responsibility to the participants, including a respectful honoring of their words and images. Their generosity and openness has touched me, and afforded me significant insights into their experience as teachers and learners involved in the pre-clinical medical education program at the University of Alberta. I

feel responsible for treating their data with respect. This sense of gratitude, however,
creates another tension. Several participants shared their enthusiasm about being part
of an artwork, and may well expect that their input is audio or visually-embedded in
the arts-based outcomes of this study. How do I respond to this expectation? Am I
obliged to employ everybody's data in the artistic outcomes of this inquiry? What if
(and it is very likely for at least some of the participants), given various aesthetic
considerations, their hands and voices, are not included in the final rendering of the
various artworks that result, but only 'inform' them?

New openings

As the ethics protocols aim to protect the participant, for instance, decrease their
vulnerability, I as an artist-researcher feel vulnerable when proceeding to exhibit the
artworks resulting from the interviews. While the majority of the participants have
agreed to be credited with their names, they have done so by viewing only two still
images: one of the photo-collage, one excerpted from the video piece. The photo-
collage *Systems-based body* (image 1) is a composition of the participants' hands,
illustrating the so-called systems-based curriculum, common in medical schools, in
which the body is divided into organ systems and the study proceeds system by
system. The dimensions of the collage are 40 x 245 cm. An exhibition will screen the
video piece *Preclinical body* (image 2) a 10-minute hybrid abstraction of a medical
lesson, employing elements from problem-based learning, clinical skills and anatomy
teaching method as part of a series resulting from my stay in the University of
Alberta at the FAB Gallery in Edmonton, opening May 15, 2012.

Image 2 Preclinical body: The video piece *Preclinical body* is constructed from 13 interviews with medical students and educators, and it explores how the body is represented in various learning contexts.

Exhibiting works in the participants' home institution is a unique way to re-connect with the participants, and I hope they find an opportunity to view the artworks in the gallery. At the same time I wish I would have an opportunity to brief them personally and continue the dialogue instead this being an end point for our relationship. I recognize a need to receive their reactions and comments from them. In fact, I think the participants could be engaged with the audiovisual sketching of the future outcomes of this research project much more; since my research project explores the various representations of the body in medical education, it would only seem natural to discuss and sketch how the students and teachers wish to be represented in their own terms. The project has unveiled some of the challenges and limitations in 'my

way of working', in which autonomy and improvisation play a great role. The official

ethics protocol, initially perceived as a hurdle, has in fact been a mirror for these

underlying ideas of professional identities and the protocol's seeming rigidity

potentially results in increased flexibility as I continue navigating the health research

field in various roles.

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