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When Touching Becomes Contact

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Abstract

For the research study In Search of Stories (ISOS), an interdisciplinary group of artists was invited to co-create an artwork with terminal cancer patients. ISOS was set up as a multidisciplinary research project to monitor the change in the experience of contingency of participants in cocreation, and, in the long run, of innovating education and health care contexts. Contingency is an often extreme, life-changing experience, like living with a terminal condition. My cocreation in ISOS became part of my PhD project in which I, an artist-researcher, investigate aesthetic interaction with materialities (bodies, objects, spaces) through the lens of Touching. I analyzed how the method of Touching generated care. I examined *How the touching of materialities (bodies, objects, spaces) unfold into contact, emerging into forms of care between artist, participant and material?* In this article, I present one co-creative ISOS process I facilitated, and critically analyze through Joan Tronto's phases of care (2017). I investigate what forms of care between artist, participant and material emerge, discussing challenges related to aesthetics, ethical issues, and working within different spaces. I will focus on how physical contact with materials like cloth, clay and (bio)plastics influence and shape the care practice of the participant and me, sharing the various artistic strategies and questions used to create non-hierarchical and emergent forms of collaboration in the context of care.

On a sunny day in May 2021, I ring the doorbell of Joan's apartment, a woman aged 68. She has been terminally ill once before but miraculously recovered. However, the cancer returned. She's too weak to visit my studio. She's now, as she would call it later, in her 'bonus time.'

Together with colleagues of In Search of Stories (ISOS), a collaboration between the University of the Arts Utrecht (HKU), the Amsterdam University Medical Centre (UMC) and Radboud University Nijmegen, we challenge the current, instrumental use of stories and materials in health care research. Among other topics, health care research focuses on telling and listening to illness stories. There is, however, little attention paid to people's aesthetic, sensuous experiences. This article focuses on that. Additionally, materialities in care matter to people who suffer from cancer. They matter greatly yet are under researched. Therefore, I will particularly focus on how physical contact with materials like cloth, yarn, thread, natural dyes, foam, clay and found objects like shells and with letters, lines and figures made with 3D print material influenced and shaped the dialogue between someone who is ill and who worked with me, an artist-researcher. I critically enquire how, when and why objects/materials are perceived as care agents and start to care for the needs of people who live with serious illnesses.

Context and Defining Care

For ISOS, an interdisciplinary group of artists was invited to cocreate an artwork with terminal cancer patients. The project had multiple goals. For participants, the project may have improved the quality of time they have left and offered a creative tool to interpret life stories, finding new meanings. For the research partners, the study focused on understanding how transdisciplinary, co-creative processes of making art works by artists and patients can support education and health care. For me as artist-researcher, I investigated aesthetic interaction with materialities (bodies, objects, spaces) through the lens of Touching, the artistic approach I develop(ed).

In this article, I present the cocreation of an artwork with one participant, Joan. We agreed to a process of interactive engagement, based on mutual sharing, connection and trust, whereby process and product are equally important and intertwined (Weeseman, 2022). Along the way, the cocreation became the primary goal, as we both considered our working together became the artwork itself. To protect the studio space from institutional deadlines and expectations about the end product, we slowed the process of cocreation which allowed for genuine care for life stories and the unfolding process.

I define care as

everything that *is* done (rather than everything that “we” do) to maintain, continue and repair “the world” so that *all* (rather than “we”) can live in it as well as possible. That world includes ... all that we seek to interweave in a complex, life-sustaining web (de la Bellacasa, 2017, p. 161, modified from Tronto and Fisher, 1993, p. 103)).

I use this expanded definition of care as it includes the possibility of materials and objects being agents of care that may help to create a new perspective on participant’s life stories.

However, did I care well? According to Tronto (2015), this evaluation depends on establishing a democratic process of assessing and meeting care needs, something I attempted by writing reflectively and posing questions to the participant continuously. My questions circled around Tronto’s five phases of care to critically analyze care practices; ‘we noted that caring well occurs when these different parts fit together’ (Tronto, 2015, p. 5). After describing the cocreation process, I will address my question of how well did I care, through Tronto’s (2017) phases of care, which together provide a holistic account of care. Tronto, a prominent feminist theorist, developed a four-phase model of care that emphasizes the complexities and responsibilities involved in caring for others. Later, she added a fifth phase (2013). These phases are:

1. *Caring About*: This phase involves recognizing the need for care. It's about attentiveness to others and identifying their vulnerabilities.
2. *Taking Care Of*: Once a need is recognized, this phase involves assuming responsibility for addressing it. It's about making a commitment to care.
3. *Caregiving*: This is the actual provision of care, requiring specific skills and knowledge. It's the hands-on work of caring.
4. *Care Receiving*: This phase highlights the perspective of the care recipient. It's about evaluating the quality of care received and providing feedback.
5. *Caring With*: This fifth phase emphasizes the importance of solidarity, trust, and democratic principles in caring relationships. It suggests that care should be a collective responsibility, not solely borne by individuals (Tronto, 2013).

My cocreation with Joan serves as a promising singular case that expands Tronto’s phases of care to include materials or spaces as important actors in care and aesthetic experience. My artistic research explores the caring ability of materialities (bodies, materials and spaces) as a creative strategy through the development of an artistic method that I have named Touching. Before I define Touching and draw connections (through the concept of touching) between my artistic research practice and

the cocreative process, I situate my artistic approach - which I refer to as “current artistic research.”

Situating Current Artistic Research

As a multidisciplinary artist-researcher with 25 years of practice at the crossroads of performance, scenography and fine arts, I create sculptural and spatial installations that invite audiences to interact with bodies, organisms, objects and materials nonhierarchically. My artistic practice is a “praxis of care” (Visse & Niemeijer, 2016:301) with attention to relationality, materiality, embodiment and with acknowledgment of political dimensions, such as asymmetry in power. My aim is to raise awareness of our *reciprocal* nature of being in the world, sharing the view of philosopher Jane Bennett on all materialities having their own form of agency and dynamic relationships with their surroundings (2009). To offer the experience of this open worldview, my installations provide time and space for the audience or participants to explore the ‘events’ created by the reciprocal relation between their bodies and other materialities.

In my current artistic research, I zoom in on aesthetic interaction with materialities (bodies, objects, spaces) through my possible method of Touching. My research is situated within the larger framework of practice as research (Nelson, 2013). In his 2013 book, *Practice as Research in the Arts: Principles, Protocols, Pedagogies, Resistances*, Nelson argues for a paradigm shift in academic research, especially within the arts. He emphasizes

that artistic practice itself can be a rigorous method of inquiry, generating knowledge and understanding. I adopted this broad understanding of knowledge production and translated it to my own research. In and through my interdisciplinary, artistic practice, I alternate between creating and presenting relational and time-based artworks, the study of literature and theory, observing, documenting, reflecting and disseminating the creation and reception processes of these works through writing, filming and teaching. As such, the roles of artist, researcher and teacher are entangled.

Within this practice, I treat the body as an area of investigation in its own right. In other words, my research is embodied, as formulated by theorist Ben Spatz (2017), that is, my own body is a tool to create with and reflect on. I consider this method as an experimental and embodied pathway into researching the interrelatedness of physical sensations and the tactile, aural and visual senses.

When I was invited to participate, I envisioned the ISOS project as an opportunity to explore my artistic approach, Touching, in collaboration with another person. I wondered, how I could share my perception and experience of care that I give and receive from the reciprocal relation with materialities with another person in a very precarious phase of life. I also wondered how my findings support devising a co-creative process foregrounding materialities as agents of care.

Three Steps Approach of Touching.

Below, I present the three steps of Touching as a possible method to cocreate, related to insights from the interdisciplinary field of care ethics.

The first step is to slow down, to focus and consciously experience physical *touching*. At this point, touching is solely understood as the material engagement with texture, weight, pressure, and temperature of bodies, objects, spaces, and the inner and outer movements the body enacts (evoked by the proprioceptive and kinaesthetic senses) in interaction with these bodies, objects and spaces over time. Instances include the awareness of another way of moving one's body, a sudden stiffness in the neck, an upset stomach, a frozen jaw.

The second step is becoming still, to remain in a state of reception, and to gain an awareness of what this physical touching makes me or you do (or not do). I call this *contact*, which I understand as the conscious, reciprocal experience of me touching and being touched. This contact induces me to yield

some agency in relation to my environment. My touching triggers the following questions: How do I answer? What will be my response?

In step three, I focus on the physical reciprocal experience of moving back and forth between touching and being in contact – an oscillating embodied attention that becomes an interval in time, or a space in between, to explore. This state of being present affords performing¹ in a vulnerable and open manner as one exposes oneself, through the distribution of agencies, to the other and the unknown. As Touching affords a physical connection it strongly influences, maybe even directs interacting with, responding to and taking care of bodies, materials and spaces. As a result, trying to answer the questions that emerge becomes a de-hierarchizing, physical experience that may evoke creative tension and new imaginations.

¹ I relate performing to the posthumanist understanding of performativity that points to the materiality of meaning-making: how discursive practices and material phenomena do not stand in a relationship of externality to one another but are mutually implicated (Barad, 2003). This builds on performing as experiencing and sensing in the moment and produce a series

of effects through the body. Influenced by my embodied cognition, my corporal literacy and societal, and political circumstances. This understanding of performing is influenced by the writings of Judith Butler and my own experiences as a performer (Butler (1988), van der Vlugt (2015, p. 21)).

Broader ISOS Goal: A Change in the Experience of Contingency

Again, for ISOS, an interdisciplinary group of artists was invited to cocreate an artwork with terminal cancer patients. This occurred in the broader ISOS context, which was focused on changing the experience of contingency. An experience of contingency is an often extreme, life-changing experience we can all have. These occurrences can be both positive and negative, such as a global pandemic like COVID-19 or a personal health crisis. It's not clear or logical why it happens to you; it's often experienced as chance or bad luck. The experience may lead to insecurity due to a crisis of interpretation, potentially disrupting a person's self-image and idea of personhood (Weeseman et al., 2023, Kruizinga et al., 2017). The situation disrupts usual confirmations of one's life story, confronting people with dimensions of life they can't get hold of or control. To comprehend and navigate disruptive, unfamiliar experiences, individuals often require a shift in perspective, developing a new sense of self from which to understand their situation (Scherer-Rath, 2013). For the participant, the trajectory consisted of different phases, monitored by the medical researchers and centred around a change in the experience of contingency (Weeseman, 2022).

ISOS is set up from the stance that stories and imagination can assist individuals in coping with contingent experiences by giving them meaning. As such, the ISOS research is related to

narrative medicine, which values narrating as an avenue towards consciousness, engagement, responsibility and ethicality (Charon, 2006). But instead of only verbally sharing and articulating experiences, during the cocreation process, working attentively and experientially with materials triggered personal stories.

Thus, as a group of artists, we worked with people who were terminally ill. When we joined the ISOS project, we participated in a preparatory training trajectory in which we gained insight into our role, also discussing ethics and responsibilities. With the participant, we aimed to cocreate a concrete 'art product' – something that could be shared with other patients, be exhibited in a gallery or become a material memory for the family, an artwork related to the specific time and place, the here and now of both the participant and the artist.

The Trajectory

This article documents the co-creation of an artwork with participant Joan. Our collaborative process, rooted in mutual sharing, trust, and engagement (Weeseman, 2022), prioritized process and product equally. The artwork emerged organically from our interactions, making the co-creation itself the primary artistic endeavor. Joan and I met several times. After every in-person cocreation session, I captured my thoughts in words, sometimes associatively and creatively to foster sensitivity for the participant and myself, sometimes reflectively to understand

what was needed for the process to continue.²

To be able to research and monitor a change in the contingent experience, participants filled in RE-LIFE questionnaires, drew lifelines, and ‘rich pictures’ at the start and the end of the trajectory³. After this practical executive phase, a variety of short stories was presented to participants. The tales, like the biblical parable Jonah and the whale or Kafka’s *The Metamorphosis*, describe characters that need to deal with a specific plot twist in their lives. Participant were invited to choose one story that appeals to or encourages them to explain something about their experience. Joan, the woman I worked with, was also invited to do this. At a preparatory meeting she was guided by a spiritual counsellor.⁴ The insights the counsellor gained from these meetings were shared with the medical researchers and with the artists before the artistic phase began.

From that point on, it was up to me to set up a series of meetings with Joan, the participant. From my role as an artist-researcher, I prioritized the cocreative, creative process to let an artwork

emerge out of the physical encounters between Joan, the participant, me, the artist researcher, and the materials without the need to have a clear design, concept or goal beforehand. It meant that I needed to be clear to myself and all parties involved that I’m not an art therapist as my work has no medical goal or health-related outcome. I sensed I needed to be very aware and clear about this position as I was functioning between two poles. On the one hand, I was in service of the participant, supporting the imagination and creation of a material shape that gives another perspective to the contingent experience while continuously being aware of her physical condition. On the other hand, the goal was to create an artwork. Both were equally important but could create tension. My role as a researcher was organically interwoven as Touching as a way of working shaped the creative process. All meetings were voice recorded, photographed,⁵ and photos were shared with various parties, including Joan.

What now follows is a description of my trajectory with Joan, based on the audio recordings and transcriptions made of the

² Some fieldnotes are integrated in this article (indented).

³ For an overview of phases in the project and an explanation of the questionnaire, lifeline and rich picture: (Weeseman et al., 2022, Bood. Z. 2019).

⁴ The task of the spiritual counselor is to step back and give the ‘stage’ to the participant, to listen and assist her in giving meaning to the personal

stories that come up in relation to the narratives. The counselor isn’t a therapist but helps and supports the participant to formulate new insights and personal realizations.

⁵ All photos included in the article are made by me during the process, unless otherwise stated in caption.

sessions, including *the fieldnotes* that I wrote during the process. The descriptions of the encounters don't do justice to the visceral content of the actual meetings; to complement the descriptive limitations, various photos have been added that present other traces of emerging care practices. The chosen textual fragments describe the process that relates to Touching, revolving around the interactions between the patient, the material and me to explore if and how this way of working becomes productive as an artistic method and as a process of care.

Meeting 1 – First Material Encounter

On a sunny day in May 2021, I ring the doorbell of Joan's apartment, a woman aged 68. She has been terminally ill once before but miraculously recovered. However, the cancer returned. She's too weak to visit my studio. She's now, as she would call it later, in her 'bonus time.'

I am anxious to meet with her. I am nervous. What to expect? How will I react to somebody with little time left? How physically ill is she? Can I put myself in a state of receptiveness to really listen to her? Let myself be Touched⁶ by her? And will she allow me in?

Joan's apartment is full of art objects from all over the world. She has lived in a great number of places and is a real art lover and a good craftsperson. She loves to work with her hands. I am impressed and feel slightly insecure as she articulates very strong and specific ideas about taste, aesthetics and art in general. Within the first five minutes of meeting, she states her idea and clear wish: she wants to make something with the bandages she saved after every chemo treatment.



I show sincere interest in the delicate material. Fingering, stroking, pulling, and measuring the bandages together helps us to become more intimate and personal. This matters to me, because it allows for trust to emerge, one of the pillars of care (Tronto, 2017). Trust not just in me, but also in the materials. Joan starts to share stories about the last months, her sickness, and how she physically feels. This material encounter also

⁶ I refer here to the second step in my artistic approach Touching explained in section titled Situating Current Artistic Research.

stimulates me to speak about my work.

We talk about the story she chose at the project's beginning phase⁷, more than a month earlier. It is the story of Phoebe, who lost her child during labour. It isn't so much the loss of the child that Joan connects with. She recognizes Phoebe's inability to express her needs to the people around her. Joan calls this the little girl syndrome: 'Even when you are almost dead, you still want to please the other person.' She firmly articulates that this is the one thing she needs to practice and develop in the time she has left: to stay close to her thoughts, emotions and needs and to express these loud and clear to others.

I have the physical sensation of being overwhelmed. My neck is tight, and I feel the need to walk. I empathize with her, but her firmness, verbal articulation, and expression of opinions as well as the collection of art objects in her house, her energy and her use of words affect me on many levels. I need to make time and space to listen to my emotions, process them and not enter into a power relationship, as in her strong stance, I sense a form of control.

⁷ In this preliminary phase, the participant can choose from a selection of excerpts of literary texts in which ways of dealing with a contingent life event are presented. The chosen story serves as a starting point for a

Meeting 2 – Slowing Down to Find a Starting Point

Joan visits my studio. Three months have passed since our first meeting. She spent the summer in her cottage abroad. To slow down the process and create time and space to integrate Touching, I collected a lot of materials for her to handle and spread them out in the atelier. She feels so much better, and her condition is stable. It changes the tone of interaction between us. Are the need and the momentum still there? We talk about her expectations and possible directions to continue working.

It's confusing. Her state of health has improved, and it feels like the urgency of the project has lessened for both of us. For her, it needs to be fun. I don't want to entertain or just give a workshop. After I talk to the team, it dawns on me that the project can still be very important for us both – a tool that helps her to live through the current moment in an intensified manner, a new phase in which she may discover and explore what hasn't been expressed. For me, a challenging opportunity to try to capture and translate our interaction in a form.

Joan clearly expresses that she doesn't have a bucket list. She

conversation with the spiritual counselor about a patient's own life story. See for more information the article (Kamp, et al., 2021).

had a beautiful life and feels like she has done it all, expressing the following many times: ‘I have been there, done that...’ When I ask if we could work with her memories, all her travels, etc., she’s very clear. She doesn’t want to dwell in the past; we don’t have to do anything with all the stories and memories she has lived through. She says, ‘I don’t want to make them into anecdotes. I want to enjoy the present moment.’ Then suddenly she states, ‘I am trying to find a manner to say politely I don’t want to work with this personal material.’

This is clear.

I ask if I can blindfold her after introducing my artistic approach Touching. She accepts, and I let her feel materials and a handmade object.

She reacts rationally, immediately expressing and guessing what



the material is, what it looks like, describing how it is made; for instance, she says, ‘This is a ball, it is foam, used during gymnastics, you cut it and then you sew a thread through it.’

However, she’s laughing a lot.

I ask her if she experienced the material touching her back. She says no.

She then notices an object I have started to make for another project, hanging on a bust.



Her body posture changes as she recognises something related to this object. She walks close and touches it. She expresses that she loves the tribal look and that she has many memories of these

kinds of objects. Her hand slides over the harsh material, feeling the stone that is hidden in the middle, and then follows the outline of the work. *It's an empowering encounter. Her energy changes.* She says that she would like to make something that looks like this, something that might be worn on the body but is an art piece.

To me, this feels like an opening, a clear starting point.

After she left, I feel a bit uncertain about how to continue. Joan's strong rational response to the Touching experiment with the object and materials makes me wonder if my explanation and experiment is sufficient to invite another person to open up to this manner of co-creating in which the materials drive the process. Maybe practical examples of me exploring the three steps of Touching with the bandages as material by myself, would help her to open up to this manner of working and we could research together what this approach might evoke.

I start to engage with the thin and delicate bandages she brought to my atelier, manipulating them cautiously and observing their behaviour. I look closely at how they expand and contract, like skin. The bandages, when pulled out of shape a bit, show a variety and composition of lines, irregular, like handwriting. With my 3D pen, I try to copy and draw these lines on top of one of the bandages.



When I tear off the bandage, the drawn lines of 3D filament become an autonomous tactile object. It feels like a lifeline that I can hold in my hands, a graphical measurement of time passing by. It also reminds me of orthography, the spelling of an unknown text.



The object invites to be handled as a sort of comb through which materials can be woven.

Thinking of her wish for a work that might be worn on the body but is art, I try to make a bracelet.



And later a necklace:



Meeting 3 – Connecting in the Here and Now

Three weeks have passed. Just before Joan comes to my studio, I send her a message by phone and ask her to bring something important to her, something that stands out for her that day. It can be anything, like an object, a text or any material. With this object, I hope to find out more about her current state and talk about the here and now and how she's doing.

Joan brings an azure blue piece of stone that she took from a pyramid in Egypt about 22 years ago. She remembered that the stone was in her possession because she had read an article that morning in the newspaper that announced the renovation of that same pyramid. She had kept the stone for all these years in a glass vase filled with shells. Here are Joan's snapshots of the vase at her house and of the newspaper article:



Oudste piramide van Egypte opnieuw open na renovatie



De piramide van Djoser -- © Shutterstock

De piramide van Djoser in het Egyptische Sakkara heeft donderdag opnieuw haar deuren geopend voor het publiek, nadat ze meerdere jaren gesloten was voor renovatie. De 4.700 jaar oude piramide bevindt zich in het zuiden van Caïro en wordt beschouwd als de oudste piramide van Egypte.

She holds the rough-edged stone in her hands, turns it around, starts to recollect memories and shares stories of her adventures while living as a resident in Egypt. When she finishes, she concludes that she was really happy there and that it would be the one place she would consider visiting again.

This is the first time Joan speaks to me about something she would like to do in the time she has left. I sense new energy both for the project and Joan.

As she rotates the stone in her hands, it becomes a turning point that allows her to revisit the place and time of her memory.

I give her a new assignment. I ask her if she can use modelling clay to show how she feels. I will do the same. While we work at the table and try using clay to show how we feel, she casually speaks about her nails that easily break as a side effect of the chemo. She has artificial ones glued on top of them. She's proud that they're still in one piece.



We talk about what we tried to express in touching and moulding the clay. We apparently both tried to depict how we experience ourselves as part of a greater network. For her, this is like nature, and for me, it relates to our mutual process. She continues by talking about her love for the sea, the seashells she assembles, the colour blue in many shades, and how the sea always stays in motion.

We pick up the bandages again.

We try to make an imprint of the pattern/structure of the bandage in the clay, but actually, it is more interesting the other way around; the colour of the clay makes marks on the bandage.

The yellow trace of clay on the white bandage, the story of her fragile nails and experiencing the delicacy and details of the thin material itself, lead us to talk about the imprints made by our own physicality, about the exfoliation of her skin and drops of blood left on the bandage during and after the chemo's, and

about the epidermis of my fingers that is so dry that the little rough ridges make frays in the fine material. I confide to her; I've started to wear plastic gloves to protect the material when working with the bandages which make me a bit clumsy as they desensitize my fingers.



After these experiments, I explain to Joan that I experienced the physical interaction between the clay, the bandages, her and me, as oscillating between touching the material—manually trying

to depict a network using clay - and making contact - noticing and responding to the interaction with the material, like putting on gloves to prevent traces on the bandages. This oscillation between touching and contact generated an intense, embodied attention to the physical, vulnerable connection between the materials and us - in which care and creative tension appeared.

The physical experience this generated, moving back and forth between touching and contact, I experienced as creatively interesting as it exposes me to something unknown conveying part of my agency to the materials and her.

I feel this is the right time to present Joan my experiments: the red necklace made of 3D pen material that materialised from the 'dialogue' I had with the bandages.



She's overly enthusiastic and states that this is why I am an artist and she's 'just' a craftsperson I feel a bit shy. However, it is clear she loves it.

It feels like I passed a test, apparently, I can create something she appreciates. I also sense relief on her side, maybe the term co-creation gave her the idea she had to take on similar responsibility as me for the whole trajectory and clarifying our roles gave some ease and air to the process. However, it is clear that she loves it. and that maybe clarifying our roles gives some ease and air to the process.

When she's gone, I decide to continue this manner of remote co-creation and do some research on the renovated pyramid in Egypt, making drawings based on Egyptian symbols for health and recovery like the eye of Horus, symbols of oneness like Sri Yantra and on the inside spirals of seashells.



Inspired by the result of her work with clay that referred to nature and sea, I wonder how I can add softer, more organic and natural materials to the 3D shapes - like connective tissue.

I start to experiment with making bioplastics⁸ and adding a variety of food pigments to colour the fluid.

⁸ https://issuu.com/nat_arc/docs/bioplastic_cook_book_3/s/159731



I also attempt to dye the bandages in different shades and dip them in bio plastic.



Meeting 4 – Exploring the Interaction Between the Materials and Us

A month has passed. Joan cancelled a session in between as she had a high fever and needed to be hospitalised for a few days. She sent me a WhatsApp message with a photo of stones, shells and materials she collected.

Joan enters and immediately says she has made me a present. It's a shawl that she knitted, inspired by our conversations and experiments, with the different colours of blue from the sea near her vacation home.



She also brought the stones from the photo and chestnuts, and she gives me a beautiful shell from Mozambique. She asked for and received a 3D pen as a present for her birthday. She said she was inspired by what it could do. However, it was more difficult than she expected when she tried to work with it.

We talk about the chestnuts she brought while holding them and experiencing their sensual shapes.



While working with the clay, she refers to the film *Fantastic Fungi*⁹ and how she's part of this overarching 'total network'; when she dies, she becomes part of the earth again, and that's it.

I show her my experiments with dyeing the bandages and testing bioplastics. She loves the colours and shapes. She's delighted. She says, 'Every time I come here, you have created a whole new world.' I praise her for the shawl; especially the shape is very inspiring. It's amazing how the outline resembles the sketches I made in my notebook related to the Egyptian symbols for health and recovery and seashells.

I ask her if she would like to continue working like this in a dialogue between the two of us through objects and making.

She answers that she just wants to continue knitting the white bandages she collected; everything else is too laborious for her. She says, 'That's the difference between us. I come here but stop with the process when I go home. You continue to work in your atelier, and you treat life as art. I find this fascinating. How your brain works, making connections between my stories and the objects I bring. This is why you are an artist, and I am not.'

Her words make me remember the list I assembled with her quotes, her words that stuck with me:

'From trash to treasure.'

'I need to buy clothing for the summer!'

⁹ <https://fantasticfungi.com/film/>

‘Bonus time.’

‘My bucket list has been empty for a long time.’

‘I have seen that, done that.’

‘If I start knitting a sweater, I will finish it as well.’

‘A book a day keeps reality away.’

‘Pippi Longstocking: I have never done it, so I will be able to do it.’

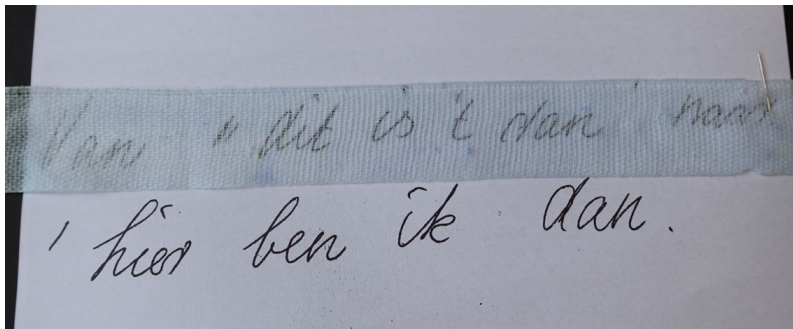
“We are so afraid of dying, that we forget to live.”

I propose we do something with these sentences, like writing them onto the bandages. She agrees and her posture changes: she grows taller...

I ask her to write down one sentence so that I could copy her handwriting. I select the one I feel related to this moment:

‘From “this is it” to “here I am.”’

Here is an image of it, in Dutch written by Joan, photocopied and enlarged:

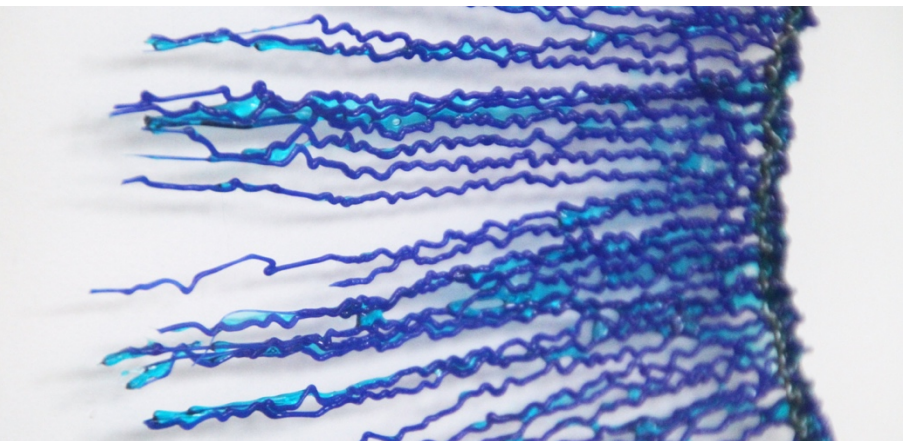
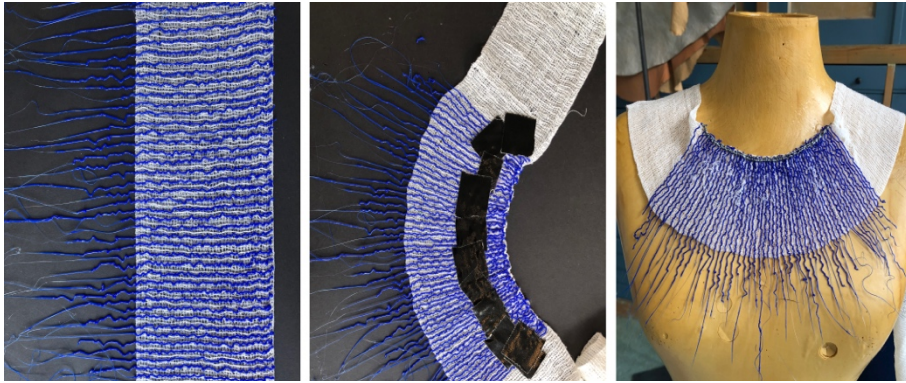


We speculate about the end product, and both agree that it needs to be the manifestation, the channelling, of, everything we have talked about.

Joan says:

For me, it became so rare that somebody asks me other things, not related to my illness. I feel seen, somebody is interested in me, takes the time to inquire, and cares about me. This process also changed something in me. I suddenly was able to take time and had the peace of mind to focus on this project, and I assembled materials and knitted with my full attention. I thought about what these gestures of care, for the material and the knitting itself, “say” to me. And that’s how I came to knit this shawl – as a gesture to you.

After she’s left, I continue to work – inspired by the different elements and topics. They feel like pieces of a bigger puzzle. It’s much work; however, the bits and pieces come together in a flow. The next two pages provide some images.



Meeting 5 – The Process as Artwork

Again, a month passes. Joan cancels one meeting as she developed a high fever again and is on antibiotics, making her fatigued.

I am partly relieved as the dyeing of the bandages took a lot of time. In addition, finding the right angles for the lines within the circle, inspired by my drawings of Egyptian symbols and the internal structure of shells, and stimulated by the knitted, shawl Joan gave me, appeared to be challenging. The choices I make are quite intuitive and need to be experienced materially, which means - a lot of redoing.

When the two works are finished, I hang them on the wall in such a manner that when Joan arrives, she won't see them immediately and I can present them to her one after the other. When she arrives, I ask her to close her eyes and lead her into my atelier.

Looking at the first work, the circle with bandages, Joan reacts like this:

So beautiful, and amazing. Some lines travel across the wall, horizontally, and the vertical lines touch the ground. I recognise the circle, the spiral, the shawl and infinity, but in the middle, there is the end. That's where it stops. We need to face that one day it will stop. I once had my aura read. I connect to the colours that spill on the ground.



The more you have your roots in the ground, the more you are connected to the earth. If you fly too high, you have already left life. I always want to have a choice. I see the opportunity for choices in the work; the choices are still there. The colours are the sea, and the path is a red line through life. It was my idea with the bandages. I never thought that this would grow out of it (Joan)..

The second work is a 3D pen structure drawn on and torn off the bandages, then poured over with blue food-coloured bioplastic.



I put it in between two glass plates for the light to shine through. Joan experiences the work as a stained-glass window and associates it with the pieces of plastic and glass she used to find on the beaches in Africa: 'from trash to treasure.' She remembers that if you look at them from a distance, these small things glitter and sparkle and look just like coral; but if you take them out of the water, they're just worthless pieces of used glass.

It also looks like an array or an ornament worn by American Indians,

worn against the direction of the wind.

Headwind.

Crosswind.

It is a little self-portrait.

She holds it in front of her face.



Joan then opens her bag and presents the white knitted piece she has created. She recounts where she found the stones with the holes and how she put them in between the threads. She explicitly points to the trace of the yellow clay that was left on the white bandage.



In the square the trace of the yellow clay.

We look at the leftovers – the coloured pieces of bandage. While touching and talking, we come up with the idea to hand knit them together.

We decide that we don't want it to be too neat; we will just make knots to attach the bandages, leaving the end pieces hanging.



She knits, and I tie.



We talk about the process while knitting together.

She says, 'I can really feel that we have created all this together, and that empowers me. This process is the artwork, as it makes me think differently about myself. You have noticed this.'

I can only agree. It has changed me, too.
I ask her if I can add a piece of the white, uncoloured bandage at the end.
She says no.
No discussion, it is clear.

Exhibition in Pastoe Factory, May 2022, Utrecht

All ISOS participants knew that the artworks would be shown on public occasions. This was part of the contract they agreed to and consent they gave beforehand. In the contract, clear agreements were made about security, transport and damage.

For Joan, the idea of exhibiting the works was exciting and added an extra dimension to the process. Although at the beginning, knowing the work was going to be exhibited might have added some tension to the process, this changed towards the end.

For example, when talking about exhibiting the works, we soon agreed that the sensitising performative process had become the motor and artistic outcome of the cocreation; the process of becoming receptive to our material engagement with texture, volume, weight and temperature and the movements the body enacts in interaction with each other's body, space and time was translated in a material, temporal dialogue that we consider the aesthetic experience or the artwork.

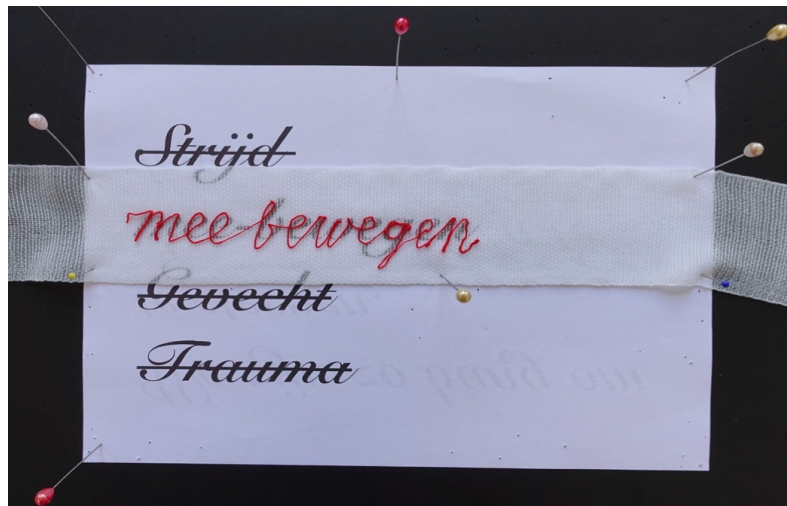
Joan became very positive about sharing her process with others and hoped the project could benefit a larger group of people living with terminal illness.

At the first exhibit opportunity, to capture the essence of our co-creative process, I constructed an expansive three-dimensional collage incorporating various artistic products. This artwork bears witness to our material exchanges, shared memories, and collective imagination, all interwoven with the complexities of our precarious work environment. The artistic process itself, including photos of the conditions that evoke Touching, inspiring our collaboration and the evolving artifacts, became the core of the final piece. Here are various images of the set up - exposition at Pastoe Factory, Utrecht.





These words were selected by Joan and her husband. They decided together never to speak about her illness using words like a *battle*, *fight* or *trauma*, as in the end, with whom was she fighting? The words they used were *to move along* (meebewegen).



Analysis and Reflection

Joan Tronto (2017) describes five phases and associated ethical elements present when care is considered in a holistic manner. Other care ethicists prefer to talk about actions instead of phases. As care ethics scholar Stephanie Collins (2015) puts it, actions can be normative claims while phases can only be described supporting the overall outlooks of the care ethicist. Rather than formulating prescriptive guidelines, I opted to critically examine the co-creative process through the lens of Tronto's care phases. My aim was to understand how 'care' could serve as a central tenet within creative endeavors. Moreover, as the ISOS framework was clear – to change the experience of contingency and explore care as a reciprocal and relational process – Tronto's phases are helpful to understand what it means to care well in a cocreative process.

Below, I reflect on the material forms of care within Tronto's various phases, and I analyzed how the method of Touching generated care. I answer the following research question: How did the touching of materialities (bodies, objects, spaces) unfold into contact, emerging into forms of care between artist, participant and material?

Phase 1: Caring About

About the first phase, Caring about, involves recognizing the need for care. It's about attentiveness to others and identifying their vulnerabilities. In this phase, the identification of needs is necessary for a care practice to come about. In the ISOS context, Tronto's first phase of identifying the need for care can be summarized for both the participant and me as the need for 'perspective change.' This need was partly identified before the artistic cocreation process started and supported the idea of care through artmaking.

For the participant, the trajectory started in the hospital. The medical team invited persons who are terminally ill to participate in the project after assessing if they were open to such a trajectory. If so, the participant was asked to browse through the various stories and portfolios of the artists and had a conversation with the spiritual counsellor. The counsellor transmitted his findings about the personal situation, the choice of story and the preference for a particular artistic medium to the team selecting the artist. Through this, the participant's need for

care already started to be explored via artistic means, via the personal preference for a story and the artistic medium.

I as an artist researcher participated in a series of preparatory interactive workshops, that provided me with insight into the entire trajectory of cocreating with a person in the last phase of her life. This assisted me in imagining what this trajectory could evoke through the exploration of personal, artistic, social and ethical dilemmas. Could we articulate our needs in this project? My identified needs for this project were a change in perspective on my artistic practice by sharing artistic agency with another person, alongside researching how Touching could be executed.

However, I found that reformulating the needs of the participant and me to accommodate this change of perspective had to be (re)done at the beginning of each meeting. It required attentiveness to the physical and mental condition of the participant at that specific moment in time, and to my own artistic needs to stay open and let the process evolve.

The cocreation process with Joan was conducted in different stages of her illness. Her physical and mental state greatly influenced the process. Joan was very tired at the beginning of the process, so the first meeting took place in her house. When her physical situation improved, she was brought by car to my art studio for us to continue the process from there.

Re-reading and re-listening the audio recordings, transcripts and field notes, I noticed the materials, objects, actions and words shared within Joan's private home space were especially influential in the needs identification and can be traced back to the end result. This is illustrated by Joan living in a house filled with art objects bought in various countries. Many of the objects were hanging on the walls or standing on drawers. She showed me around as in a proper gallery, pointed out material and aesthetic qualities – 'from trash to treasure' – and talked about her own love for knitting. Some of the aesthetic qualities of these objects, meant to hang on a white wall, realised from 'cheap' materials and related to clothing/costumes, can be retraced in the final assemblage.

When Joan invited me to her house for our first meeting, I brought various materials and objects to present her but left them in my bag as she quite soon put her idea to work with her bandages on the table. As I was a little overwhelmed by this, her choice of words and all the art objects in the house, I didn't offer my artistic input and used this first encounter for us to get to know each other, trying to attune myself to what was emerging because of our interaction.

Her choice of Phoebe's story, which we talked about in the first meeting, and what she took from that brought forward an implicit quest that I experienced in the cocreation process; Joan firmly expressed her need to explore how to stay close to her

thoughts, feelings and needs and express these loud and clear to others. In my field notes, I read back that I needed to make time and space to listen to my own emotions and trust my artistic skills.

This subtle exploration of authorship and the shifting of power balance related to the materials and the artistic ideas remained present throughout the process.

On the other hand, the material she proposed, her bandages of every hospital treatment, strongly revealed her inner state and physical vulnerability. The material was intimate and delicate making me feel like touching her body. It was her whom I was holding in my hands: *her lifeline*, I was asked to write. It's only in retrospect I understand more about the 'weight' of what I was working with, and how that informed this first phase of identifying *needs*. Of course, at that very moment, working with Joan felt personal, even though she only showed me a small portion of her collection of bandages at the first meeting. I believe she probably was figuring out, through sharing the material with me, whom she had in front of her, and if I could 'hear' her needs, assist her in articulating them, and take responsibility (the next phase) and be responsive to her needs (third phase). Moreover, as she was a knitter herself, someone who loves to physically feel the wool and materials in her hand, I experienced the sensation that she wanted to see if I had a similar preference and in what ways we were alike. The

bandages turned into material that could show her if and how I would take care of her.

The first moment I took the bandages in my hands, I physically experienced crossing a threshold; our touching each other, via the material, turned into momentary contact. However, I experienced that this trust needed to be set up every time we met.

Phase 2: Caring for

Once a need is recognized, this phase involves assuming responsibility for addressing it. It's about making a commitment to care. The caring for phase requires someone to take responsibility to make certain the identified needs are met.

Joan was my first participant. As such, the framework of cocreation was something to explore for both of us. Especially in the first meeting, it was unclear who would take responsibility to make the artistic process unfold. I slowly discovered that it was important that I actively took responsibility for the process while keeping open what the result would be for Joan to be involved as much as possible, both conceptually and practically.

The complexity of establishing this clarity was that I experienced Joan using the process as a self-investigation of how she herself related to the making of art. She's a true art-lover, had visited a lot of exhibitions, had bought many artworks, and

was an experienced knitter herself. During the process, she would frequently verbalise the differences between me and herself in relation to the actual making. This comparison of our skills, which I sometimes experienced as 'judging,' is probably why the actual making, working with the materials towards the final product, only happened privately. We both made or brought something from our own spaces and then presented it to each other during our live meetings. It felt like an exchange of gifts, which pushed forward the process.

During the process, the roles had to be clarified. Joan needed me to be the 'artist,' as it took the weight off her shoulders if the responsibility for the process and the outcome were on me. Moreover: being an artist-researcher conducting Touching as research method provided a clear and communicable reason to focus on the process, to step out of the cocreative making process at times and to take some distance to proceed.

Only after the two final products were finished did we sit down together at the table and work side by side with the leftover material, knitting a sculptural scarf.

Phase 3: Caregiving and Phase 4: Care Receiving

Caregiving is the actual provision of care, requiring specific skills and knowledge. It's the hands-on work of caring. The subsequent phase, Care receiving highlights the perspective of the care recipient. It's about evaluating the quality of care

received and providing feedback. I am combining these, as – just like with the previous phases – I experienced these are closely entwined and hard to disentangle for the purposes of analysis. Questions regarding competence¹⁰ and responsiveness are triggered: is this the best care for this specific situation? And who decides? As Tronto writes: ‘care is not complete until the need is met.’ When the quality of care is discussed, often a new need appears, and the process starts over again. ‘Needs never end until we die’ (Tronto, 2015, p.7).

In this cocreative artistic process the materials were the leading actors in evoking both caregiving and care receiving. It did take some time and effort for both of us to become responsive to the materials as competent caregivers.

Once again, for me, phases three and four were completely entangled, and seem comparable to step three of Touching, in which I keep my focus on the space in between touching and contact with the materials. During the process, there were a few noticeable thresholds that needed to be overcome to push the creative process further. As an example, I will describe one shortly.

After the first meeting, I took some bandages to the atelier. I observed their behaviour and pondered the questions the material posed. After holding it in my hands, stretching and pulling it for quite some time, I noticed the lines that formed the bandage. I felt compelled to make them stand out by using the 3D pen and redrawing them on top of the bandage. This is how the material affected me: by taking care of my desire to start the making process. After some time, the delicate material needed to be cared for. As my dry fingers had rough ridges, I started to wear thin gloves to cherish the fragility of the material.

For Joan, it took some time to consciously receive the care the materials were providing her with. Although she went along with my working proposals, like using clay to express how she felt, bringing an object that was important to her or mirroring my manner of handling the materials, she understood them rationally, as material to use with a specific goal or as a tool to evoke memories and to help her formulate changed life values and goals.

A tipping moment was when she told me during the third

¹⁰ In the podcast *Philosophizethis*, Stephen West rearticulates Tronto’s phases as virtues to be developed if you want to apply an ethics of care to things in your life. These virtues in order are Attentiveness, Responsibility, Competence, Responsiveness and Plurality.

meeting that she suddenly was able to take time to assemble materials and knit with her full attention. She said, “I thought about what these gestures of care, for the material and the knitting itself, ‘say’ to me. And that’s how I came to knit this shawl – as a gesture to you.” It is interesting to see how Joan during the process developed herself into a competent receiver for the care the objects and materials could give her. In this particular moment caregiving and care receiving became completely entangled: as listening to the material is slowing her down, receiving care from the material while knitting with full attention. In this process, she not only cares for herself, but she also cares for the material and the shape that comes about taking into account the communal process so far and simultaneously is inclined to create a gesture of care for me.

For my part, I experienced sharing this spiritual process and this open and respectful attitude towards the making process as a generous act of care from Joan to me. As the trust between us grew during the process, I experienced the time between touching and contact becoming shorter and shorter. I believe the cocreation process stimulated this. It was a slow scaffolding of gestures of care that supported the triangle of communication between Joan, the materials and me and that became more engaging and more productive.

While we shared the final products, the triad interaction felt like an ongoing and fulfilling oscillation between caregiving and

care receiving that involved all materialities (bodies, objects, spaces) in a reciprocal, open relationship.

I have found that Touching can be a productive method to foreground materialities (objects, bodies, spaces) as agents of care within an artistic practice, specifically in these phases 3 and 4, caregiving and care receiving. Tronto (1995) identifies a durational transition or a clear difference between these two phases, as she mentions the two terms separately. I found, when I physically connect with materialities, recognizing them as care agents, an oscillation between caregiving and care receiving is evoked that invites me to perform an action based on care.

Phase 5: Caring with

According to Tronto (1995), caring with relies upon trusting an ongoing cycle of care to meet our caring needs. This fifth phase “imagines the entire polity of citizens engaged in a lifetime of commitment to and benefiting from these principles” (Tronto, 1995, p. 14). This phase looks at processes of care at a social and political level, how can we even out inequalities?

As ISOS was set up as a multidisciplinary research project with different goals, many voices needed to be cared for. The question evoked by this fifth phase is, if this plurality in needs was sufficiently identified and if care could be given on an equal and consistent basis. For practical reasons, I will approach these questions from three perspectives: from the participant, the

family and the organisation, but I do acknowledge, my case study doesn't really allow for these perspectives as they weren't part of my initial focus.

On the level of the cocreative artistic process, I experienced some tension between Joan and me in the beginning, however mutual trust was actively built on during the ongoing cycle of care that was represented in how we worked with the materials.

To build this trust, I needed to set up a clear framework. I decided on a few conditions before the process started: maintaining an open-ended work process by insisting on not having a specific goal in mind while at the same time being aware of my responsibility with regard to the development of the making process (how to keep the participant involved and curious) in order to 'finish' the project with a 'satisfying' result in time.

After every meeting, I sat down and thought through what happened, listened to the audio files, and 'experienced' Joan's practical input again while simultaneously working with the materials she had touched. After this reflective, practical intermezzo, I would think of the next steps, devising the 'proper' strategy to proceed. Every time we met, I would come up with a certain proposition and/or surprise to give the process new input. The fact that I continued the work in between our meetings seemed to support the trust Joan had in me. Moreover, as she

told me, it made her curious, as at every meeting she got a new insight or changed her expectations or preconceived ideas.

On the level of the family, I found the need for care was not sufficiently recognized as Joan's spouse didn't feel included in the process. Joan's spouse came to me when the artworks were exhibited. He felt really excluded and wanted to let us know that there should be a parallel trajectory of care offered to close family of project participants. Of course, he was told about the process and saw how proud Joan was, talking about and showing the works to friends and family. But he was never asked about his needs nor given personal attention within the scope of the project. As Joan never told me anything about his feelings, I didn't know about them, but I understood completely that this should be done differently the next time. This may have been a missed opportunity to process his experience of her contingency.

Thirdly, there was the organization of the whole research trajectory and process. As previously described, the artistic process was only one part of the full trajectory, and the participant and I needed to fit into the larger framework. In other words, the cocreative practice can be viewed as a shared undertaking in which the participant and I continuously respond to the materials and external influences, such as a funding agency or steering committee. This undertaking wasn't without tensions, as experienced when there were external influences such as time pressure and the fact that a final material outcome

needed to be realised to be able to set up a public exhibition and meet the requirements of the funding agencies. To maintain a safe space to work in, to foster care through safety, I kept most of this dialogue with the organisation away from Joan.

As these three perspectives and examples show, caring with is dialogical and places responsibilities at the centre of the cocreation process. However, a material practice is never without tensions or asymmetries, and these factors impact our vulnerability and precariousness. As Tronto (2015) puts it, care is always infused with power, and this makes care deeply political.

Conclusion

In this cocreation process, the materials and objects were perceived as agents of care and supported the participant in gaining a new perspective on her life story and me in gaining another perspective on my artistic process.

From this cocreation process, care needs to be seen as a closely entwined process; never finished. The five-phase approach is helpful to disentangle the cocreation, but only temporarily, as reality is complex and less linear. Attentiveness remains relevant in all phases. Every phase requires specific responsibilities and needs to be attuned in conversation with the people with whom one works.

I regard Touching as a method of research as I was able to share this method with the participant, and I repeated the steps multiple times. At first, Joan said she couldn't "let the materials talk to her" as she found it difficult to be in the moment and open up to an embodied, relational approach to the materials. However, at the same time, her body already seemed to respond differently as she was laughing a lot while holding the materials in her hands. Returning to Touching multiple times Joan started to perform gestures of care with her knitting and sharing of objects.

This supports the idea of adding Touching as research method to Tronto's concept of holistic care. During Tronto's phases three and four, I would add the challenge to give time and space, going through steps 1-3 of Touching to consciously identify when, if and how materialities have become agents of care. I am not proposing changing Tronto's theory or ethic of care, but I would like to invite readers to consider Touching as an entrance to relate to materialities of care.

As physically handling, knitting, painting, ripping, combining, moulding and shuffling the materials enabled us to discover and play with memories, words, gestures, movements and shapes. By giving attention to our embodied sensations evoked by these physical connections, by the different scales of touching and being touched, Joan and I were evoked to perform other, new and imaginary actions that care, presenting our reciprocal and

relational being in the world.

As competence and responsiveness to materialities are key in these phases, and (might be) needed to perform artistically, consulting an artist-researcher can become very relevant in health care research.

To further develop the method of Touching in relation to forms of care, the following questions come to mind: Are there direct connections between the qualities of the material (texture, colours, weight, temperature, softness, etc.) and the forms of care they evoke? Or is how we handle the material, such as cutting, caressing or ripping, more influential for what we pay attention to, how we think about responsibility for what we do?

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