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FULL-LENGTH ARTICLES

What "Coproduction" in Participatory Research Means From Participants' Perspectives: A Collaborative Autoethnographic Inquiry

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In participatory health research, people with lived experience of illness participate as co-researchers in the co-production of knowledge along with academic researchers. A central idea is to democratize knowledge production by creating space for co-researchers' experiential, embodied knowledge. The participatory research literature includes reflexive analyses exploring the complexities of co-production in participatory research. However, despite the democratic ideals, these analyses are almost always written by academic researchers alone. In this article, two co-researchers with lived experience of Parkinson's disease and an academic researcher carry out a collaborative autoethnographic inquiry into what "co-production" in participatory research means for participants *from their own perspectives*. In so doing, the article presents and illustrates a distinctive format for collaborative autoethnography as a participatory method that enables co-researchers and academic researchers to investigate, write, and publish about co-production together through dialogue across personal narratives. It also presents the specific insider insights the inquiry generated into what co-production means for participants.

Introduction

Across the diversity of approaches to participatory health research, a central feature is that co-researchers with lived experience of illness and academic researchers co-produce knowledge in specially designed fora (e.g. Abma et al., 2009; Banks et al., 2019; ICPHR, 2013). In common with the wider field of participatory research, participatory health research approaches share the ideal of democratizing knowledge production on the basis of an expanded epistemological understanding of *what counts as knowledge* and *whose knowledge counts.* Pursuing the ideal of democratization entails challenging

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[c] Lotte Mengel is a retired district nurse who worked in the Danish health care system for about 40 years. She is 66 years old and was diagnosed with Parkinson's the year she turned 60 and had to stop working as a district nurse and retire at the age of 62. Since then, she has built an everyday life with many activities including Parkinson's dance. She is also on the editorial board of the graphic novel that is a product of the collaborative story-telling workshops in the participatory research project "Dancing with Parkinson's".

traditional knowledge hierarchies and making space for co-production across different knowledge forms and, in particular, the experiential, embodied knowledge of co-researchers (e.g. Heyen et al., 2022; Johansson, 2014; Read & Maslin-Prothero, 2011). Participatory researchers understand "co-production" as relational practices of mutual learning that contribute not only to the research field but also to social and practice changes benefitting co-researchers and their communities (e.g. Groot et al., 2019; MacFarlane & Roche, 2019; Phillips, Christensen-Strynø, et al., 2021; Phillips et al., 2013; Phillips, Frølunde, et al., 2021). According to this understanding, mutual learning builds on personal relationships of mutual care. Researchers strive to nurture mutually caring relationships throughout the research process, sometimes working explicitly with principles of relational ethics (e.g. Groot et al., 2019; Phillips, Christensen-Strynø, et al., 2021).

There is a body of participatory research that reflexively explores processes of co-production, including how power is always in play as certain knowledge forms dominate and others are marginalized (e.g. Groot et al., 2019; Kristiansen & Bloch-Poulsen, 2020; Olesen & Nordentoft, 2018; Phillips, Christensen-Strynø, et al., 2021; Phillips et al., 2013; Phillips, Frølunde, et al., 2021). In spite of the democratic commitment in participatory research to making space for co-researchers' experiential, embodied knowledge, these reflexive analyses of co-production are almost always written by the academic researchers alone; analyses of co-production carried out and written collaboratively by academic researchers and co-researchers are very rare exceptions (e.g. Arieli et al., 2009; Groot et al., 2019; Gustafson et al., 2016, 2019; Schipper et al., 2010). As Gustafson et al. (2019, p. 21) put it, "the hierarchical processes of writing and the traditional rules for knowledge production that organize the structure and textual form of scientific knowledge are reinforced in the publication arena."

While collaborative analysis and co-authorship by co-researchers and academic researchers are very rare, many academic researchers co-write autoethnographic analyses of their personal experiences. Autoethnography is a creative, arts-based methodology aiming to democratize knowledge production in line with the social constructionist and poststructuralist understanding that all knowledge is a product of situated, relational, and power-imbued practices of representation (see Bochner & Ellis, 2016). Through stories about the researcher's personal lives, autoethnographic texts invoke experiential, embodied, affective/emotional, and aesthetic knowing and relativize researcher-truths as situated and partial. In addition, exponents of collaborative autoethnography and duoethnography stress the democratic aspiration to give equal weight to all collaborating writers' lived experiences (e.g. Chang et al., 2013; Grant & Radcliffe, 2015; Hernandez et al., 2017).

Most often, autoethnographies are not part of projects that are designated "participatory research," and, frequently, they are stand-alone studies in which the researcher/researchers is/are the principal object(s). In this article, we bridge the traditions of participatory research *and* autoethnography to develop collaborative autoethnography as a participatory method embedded in participatory research. We propose and illustrate a format for collaborative autoethnography that enables co-researchers outside academia and academic researchers jointly and reflexively to investigate, write, and publish processes of co-producing knowledge in participatory research. By opening up for dialogic, embodied learning about what co-production in participatory research means from participants' personal perspectives, our format represents a way of working reflexively with relational ethics that is based on recognition of the inevitable play of power in collaborative research relations (Phillips, Christensen-Strynø, et al., 2021).

The participatory research process on which our inquiry is based was part of a research project on dance for people with Parkinson's disease and partners. Two of the authors—Anders and Lotte—are among the participants in Parkinson's dance classes who have taken part in the project as co-researchers. The first author—Louise—is one of the three academic researchers in the project, all of whom are from Roskilde University. The project had two main aims: one was to generate knowledge about the possibilities and challenges which arise in the tensions in processes of co-production in participatory research; the other was to generate knowledge about the multiple meanings of Parkinson's dance as an integral part of everyday life. This article is one of several publications geared to the first aim (see also Phillips, Christensen-Strynø, et al., 2021; Phillips et al., 2022; Phillips, Frølunde, et al., 2021). For publications geared to the second aim, see Christensen-Strynø et al. (2021; Christensen-Strynø, Frølunde, et al., in press; Christensen-Strynø, Phillips, et al., in press) and Frølunde et al. (in press).

In our collaborative autoethnographic inquiry, we draw – from our respective positions as co-researchers and academic researcher – on our personal experiences of the collaborative storytelling workshops that formed the primary fora for the co-production of knowledge. These workshops took place after a six-month ethnographic study in which the three university researchers actively participated in five different weekly dance classes for people with Parkinson's disease and their partners in Copenhagen and environs and also carried out qualitative interviews about Parkinson's dance experiences with the dance teachers and 43 dancers from the dance classes. Twenty-eight of the dancers accepted the invitation to participate in the collaborative storytelling workshops as co-researchers. To open up for embodied, affective, and aesthetic knowing, the workshops were based on arts-based methods (see e.g. Foster, 2016; Leavy, 2019).

In the first three workshops, the co-researchers analyzed extracts from the ethnographic interviews in creative exercises using the arts-based research methods of writing as inquiry (postcards and haiku poems), podcasts, and dance improvisation. The point of using interview extracts was to anchor the co-production of knowledge in the workshops in the co-researchers' personal experiences of Parkinson's dance as an integral part of their everyday lives (see photos 2, 3, and 4).

Building on the knowledge that was co-produced in the first three workshops, the final two workshops revolved around developing ideas for a graphic novel (Frølunde et al., in press) which is the centerpiece of the project's research dissemination strategy. The focus was on generating complex characters and storylines and involved enacting specific scenes where the characters interacted, using the arts-based method of dramatized role play (see photo 7). For a description of the workshop exercises and the arts-based methods used, see Figure 1: Collaborative storytelling workshops.

Our collaborative autoethnographic inquiry addresses the following question:

- What does "coproduction" in participatory research aiming to invoke experiential, embodied knowledge mean for co-researchers outside academia and for an academic researcher?

Following the ideal of democratizing knowledge production, we claim that, by creating a space for dialogue across personal narratives from different participant positions, differences can be mobilized as a dynamic leading to the co-production of new knowledge (Pedersen, 2021; Phillips, 2011). In the argument for their approach, evocative ethnography, Bochner and Ellis (2016, p. 81) assert that, in common with conventional analyses, personal narratives contain analyses in which we interpret our own and each other's experiences. They point out, too, that personal narratives have an added potential: with a "personal, vulnerable, reflective, self-conscious, self-reflexive, and narrative voice," we can *evoke* in ways that make people "feel deep in their guts and in their bones" (Bochner & Ellis, 2016, pp. 53, 63). Thus, our assumption, with inspiration from Bochner and Ellis (2016), is that collaborative autoethnography provides a method for engaging in experiential, embodied, affective, and aesthetic knowing in which we three authors emotionally move and learn from one another in dialogue across our personal narratives and also touch readers so that they "respond viscerally" (Bochner & Ellis, 2016, p. 55). Therefore, we hope that you, as readers, can gain insights through a dialogic process in which our narratives relate in different ways to your own lives (Bochner & Ellis, 2016; Frank, 1995; Gannon, 2006).

The distinctive format of our collaborative autoethnographic inquiry consists of personal letters and a subsequent conversation in which we invoke and cultivate our own experiential, embodied knowledge about the participatory research process. Here, we are inspired by Pedersen (2021) who has developed the format in collaborative writing with (exclusively) academic researchers. Crucially, the genres of personal letters and conversations are well-suited for telling stories and directly soliciting both each other's and readers' responses (Larsen et al., 2021; Pedersen, 2021).

In the following, we describe the inquiry process and present the collaborative autoethnography: the dialogue between the three authors in which we exchange and respond to personal narratives in letters and a conversation. In conclusion, we reflect on: 1) the specific insider insights generated into what “co-production” means from participants’ perspectives; and 2) our distinctive format for collaborative autoethnography which we offer as a participatory research method enabling co-researchers outside academia and academic researchers to investigate, write, and publish about processes of co-production together in ways that invoke experiential, embodied, affective and aesthetic knowing.

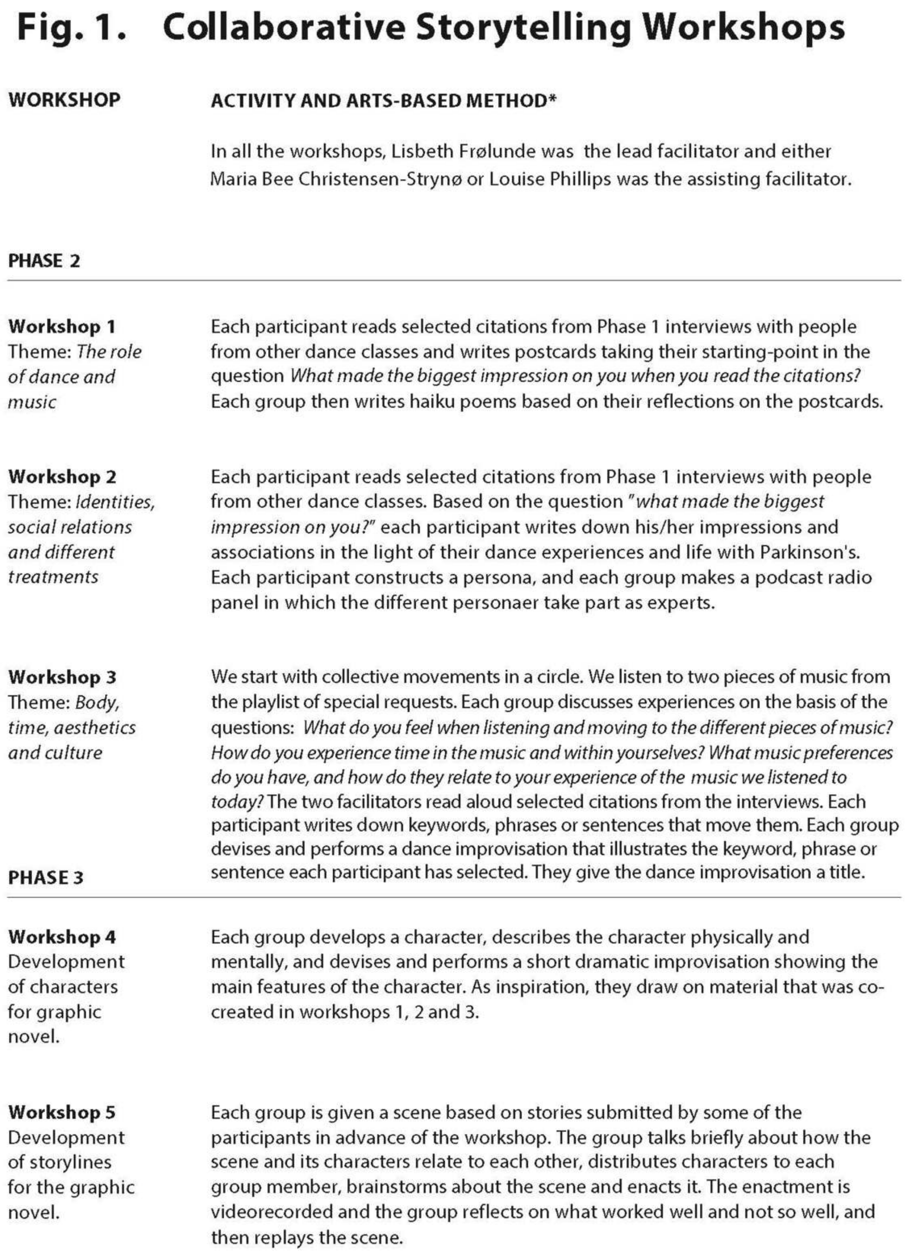

Fig. 1. Collaborative Storytelling Workshops

WORKSHOP	ACTIVITY AND ARTS-BASED METHOD*
	In all the workshops, Lisbeth Frølunde was the lead facilitator and either Maria Bee Christensen-Strynø or Louise Phillips was the assisting facilitator.
PHASE 2	
Workshop 1 Theme: *The role of dance and music*	Each participant reads selected citations from Phase 1 interviews with people from other dance classes and writes postcards taking their starting-point in the question *What made the biggest impression on you when you read the citations?* Each group then writes haiku poems based on their reflections on the postcards.
Workshop 2 Theme: *Identities, social relations and different treatments*	Each participant reads selected citations from Phase 1 interviews with people from other dance classes. Based on the question *"what made the biggest impression on you?"* each participant writes down his/her impressions and associations in the light of their dance experiences and life with Parkinson's. Each participant constructs a persona, and each group makes a podcast radio panel in which the different personaer take part as experts.
Workshop 3 Theme: *Body, time, aesthetics and culture*	We start with collective movements in a circle. We listen to two pieces of music from the playlist of special requests. Each group discusses experiences on the basis of the questions: *What do you feel when listening and moving to the different pieces of music? How do you experience time in the music and within yourselves? What music preferences do you have, and how do they relate to your experience of the music we listened to today?* The two facilitators read aloud selected citations from the interviews. Each participant writes down keywords, phrases or sentences that move them. Each group devises and performs a dance improvisation that illustrates the keyword, phrase or sentence each participant has selected. They give the dance improvisation a title.
PHASE 3	
Workshop 4 Development of characters for graphic novel.	Each group develops a character, describes the character physically and mentally, and devises and performs a short dramatic improvisation showing the main features of the character. As inspiration, they draw on material that was co-created in workshops 1, 2 and 3.
Workshop 5 Development of storylines for the graphic novel.	Each group is given a scene based on stories submitted by some of the participants in advance of the workshop. The group talks briefly about how the scene and its characters relate to each other, distributes characters to each group member, brainstorms about the scene and enacts it. The enactment is videorecorded and the group reflects on what worked well and not so well, and then replays the scene.

Figure 1. Collaborative Storytelling Workshops

The Collaborative Autoethnographic Process

Louise began the process by writing an invitation email to Anders and Lotte (see Invitation Mail). In the email, she attached a proposal for a roadmap for the inquiry, which Anders and Lotte approved when they accepted the invitation (see Suggested Roadmap).

Invitation Mail

Dear [co-researcher]

I hope all's well with you in spite of the pandemic. I would like to invite you to write an article together with me and another co-researcher who participated in the research project workshops. The idea is that we will jointly investigate what "co-production" in a participatory health research project means for the participants. We will take as our starting point our experiences in the workshops in Autumn 2019 and Spring 2020. I am inviting you because, in workshop 5 in June 2020, you took part in a drama improvisation about "the old tree" in a small group with me as facilitator.

The process will be based partly on writing to each other and partly on talking together. We will end up with an article that you, the other co-researcher from the group that worked on "the old tree," and I write together. I will make sure that the article reaches many people through the project's website and other channels. I've enclosed a suggestion for a roadmap. I hope you'd like to take part but I'll understand completely if you don't have the time. If you'd like to talk to me on the phone before making up your mind, please let me know.

Warm wishes and good weekend

Louise

Suggested Roadmap

STEP 1	Louise will write a letter of approx. one page to Anders and Lotte. In the letter, she will take the following question as her starting point: *Which experiences from the workshops do you remember the most clearly and why?* Louise will email her letter to Anders and Lotte by 10 November 2020.
STEP 2	Anders and Lotte will write a letter back to all three of us based on the following questions: *What came to mind when you read Louise's letter? Which concrete experiences from the workshops do you remember the most clearly and why?* Anders and Lotte will email their letters to the others by 24 November.
STEP 3	We will have a two-hour conversation at Louise's house which takes its starting point in the following question: *What made the biggest impression on each of us when we read each other's letters?* We will record the dialogue on a digital voice recorder.
STEP 4	Based on the three letters and the dialogue at Louise's house, Louise will draft the article. The draft will contain excerpts from the three letters as well as excerpts from the conversation. Louise will email the draft article on 4 December.
STEP 5	Anders and Lotte will comment on the draft at a meeting at Louise's house on 16 December. [*This meeting was held online on Zoom due to a tightening of the coronavirus restrictions- see photo 1*]
STEP 6	Louise will take the comments into account in revising the article and will send it to Anders and Lotte in mid-January 2021.
STEP 7	Anders and Lotte will read and comment on the draft article again at Louise's home [*The meeting was held online on Zoom due to the continuing coronavirus restrictions*]. Louise will take the comments into account in preparing a new draft, which we will ask selected readers to comment on, including the research project's advisory board. Based on readers' comments, we will prepare the final article.

Photo 1. Our collaborative writing after the conversation (step 5) took place during the height of the pandemic so we met on Zoom

Photo: Anders Larsen

Photo 2. Louise and Lisbeth plan a workshop

Photo: Anders Larsen

Photo 3. Partners of people with Parkinson’s also took part in the workshops as co-researchers—Lotte together with Anders’s partner, Birgitte, and Evy.

Photo: Anders Larsen

Photo 4. Finale of a dance improvisation: new possibilities emerge for someone with Parkinson’s

Photo: Anders Larsen

The Letters

All letters were translated by Louise and are the full, unedited texts.

Louise’s letter

Valby, 10 November 2020

Dear Anders and Lotte,

Thank you very much for wanting to be part of this process which will culminate in a joint article. I am really looking forward to the process! The idea is that we jointly investigate what it means to be part of a participatory research project - where we take our starting point in our own experiences from the collaborative storytelling workshops. I’m excited about the process and what’s going to come out of it. Where will our fingers on the keyboard and our voices in the conversation take us? What knowledge are we going to create together in the letters and the conversation? Which points from our workshop experiences will end up as central themes in the article?

Now I’d better address the question, “Which concrete experiences from the workshops do you remember the most clearly and why?” In the workshops, I was mostly on the sidelines as Lisbeth was the main facilitator with the overall responsibility for framing and managing the processes of co-production. Together with Maria, my role was to be a co-facilitator who stepped in when it made sense.

The experiences I remember the most clearly are the times when I acted as the facilitator of group work. For example, I can clearly remember that I was quite anxious when I had to facilitate group work in workshop 3 on the themes of body, time, aesthetics and culture. My anxiety was linked to the fact that it was a creative process where it wasn’t clear in advance how to solve the task, and I had the responsibility as facilitator to ensure that the process ended up with a “solution” - a product that could be presented to the others. The product was to be a dance improvisation, where the group created dance movements that expressed the essence of words from excerpts of interviews with other co-researchers (for a description of this group work exercise, see Figure 1: Collaborative Storytelling Workshops, Workshop 3). Dance improvisation was something you had to figure out together. This “you” became a “we” when I joined the dance improvisation as a dancing participant. I was supposed to be a skier colliding at the exit to a ski lift with you, Anders, who played another skier who had just jumped off the lift to ski down La Grande Motte Piste, starting at 3.5 kilometers altitude. Evy was supposed to imagine being the rescue helicopter that was called. The point of the dance improvisation was to express the dilemma Anders experiences when he wants to continue to engage in activities such as skiing although he is worried about exposing others to danger if his Parkinson’s leads him to lose control of his body.

I recall my relief when we tried out the movements and I thought it made sense as a solution to the task. I also recall the joy and satisfaction when we presented it to the others and when I saw the other group’s improvisation which you, Lotte, were part of. And I remember the sense of togetherness and warmth in the room, which I sensed when, in the two groups, we created something together with our bodies and movements. Something else that stands out clearly in my memory is *a co-researcher's concluding reflection on whether the bodily movements in the dance improvisation brought new learning or knowledge with them, or whether we were just illustrating a knowledge we already had. I think that this reflection was very exciting in light of the aim of the workshop to further embodied learning through dance.*

I also have a vivid memory of the group work with the tree in our last workshop. You, in a group of three co-researchers, had to write and perform a scene based on a story about an old, decrepit tree. The tree had been struck by Parkinson's and knocked over, but still new branches were growing. In the dialogue, the group had to play different characters who go for a walk in the woods and talk about, and with, the tree. The point of the group work was that the scene could subsequently be used in the development of plot sequences and dialogue for the graphic novel. I didn't think it would be easy and I was more nervous than I'd been during the dance improvisation exercise. This was because it was clearer this time what the "product" was to be used for - to provide input for the development of the graphic novel. I remember it all fell into place when you, [Lotte], said you wanted to be "the tree". And we all thought it was funny and nice that you already looked a bit like a tree with your blouse with leaves and flowers on it - as if it was "meant to be"! I was relieved when the story of the tree began to take shape through your suggestions to each other about what the tree could say and the others could say to the tree. I was moved by the very process of creating something together in a creative dialogue where each person came up with suggestions based on what the other said. And I felt your dialogue resonated with what I had heard in the previous workshops. I thought, "this is bound to be a good contribution to the development of the graphic novel."

I look forward to hearing from you.

Best wishes

Louise

Anders's letter

Smørum, 22 November 2020

Dear Lotte and Louise

Thank you for your letter, Louise, and thank you for the opportunity to be part of this exciting project. I have been looking forward to writing this letter. Your letter, Louise, makes it easy to get started. I would like to present some general thoughts before answering the questions [see Suggested Road Map, Step 2]. I have to be active in terms of how much my life is dictated by the disease versus how much I try to live the life I used to live. That means I have to make judgements as someone with Parkinson about whether the things I do are worth doing.

It's difficult to decide which Parkinson's activities to participate in and which not to. Maybe it's naive to think you can. I go to the physiotherapist and dance with my wife. If I didn't like my physiotherapist, I wouldn't go. I've just got home from table tennis where I won a lot of matches (and lost a few). When I play table tennis, most people don't know they're playing with a sick man. It's no secret that I'm ill; but sometimes it's nice to be free of people looking at me through a filter called Parkinson's. So I'm a bit critical about how much I want to be identified with the disease. As an ill person, you know very well that the disease develops; but that's probably something you suppress in everyday life. It is a well-known fact that one of the worst places to be for an ill person is in the waiting room of an outpatient clinic. And you have a good look at the clientele both at dance class and as a co-researcher in the storytelling workshops. This also applies to other illnesses.

But, in the case of this project, I thought Lone [the dance teacher of Anders and Lotte's dance class] vouched that it would be worth our while. And it was fun that the project is based at Roskilde University where I've been employed as a part-time lecturer for about 20 years. And although we work narratively and not representatively, Parkinson's dance requires that the participants are not too ill. So the question is, how widely applicable can our narratives be?

The setting has been great and the researchers and project coordinator were happy just because I came. I thought to myself that it's good it's not my responsibility that something sensible comes out it! I've had that thought every time we've met. What can the postcard exercise be used for? [see Figure 1: Collaborative Storytelling Workshops, Workshop 1] I have researched, or, more precisely, organized research, most of my working life. That's why I think of the concept of co-researcher as contradictory. Compared to let's just call it critical positivist research, in which a hallmark is that the researchers refrain from tinkering with the data. With the concept of co-researcher, the researcher and the data are mixed together.

Louise, you asked me to think about what aspects of the workshops were hard. I think every workshop was hard. Every time, I thought something along the lines of "What am I doing here?" But you are all so nice and the rooms are nice and bright and the refreshments are good and everything is well organized. So it just wouldn't do to get up and leave, saying "this isn't something I can do." The different workshops followed the same model. When the introduction with instructions was over, we had to do an exercise that was foreign to me.

The skier [for a description of what this group work was about, see Louise's letter and Figure 1: Collaborative Storytelling Workshops, workshop 3]: I had a bit of a crisis because dancing creatively enough is not a discipline for men. It's not something I've done much. The point of the dance improvisation about the skier: the criticism would be fierce if I were to hurt anyone on skis on account of Parkinson's. And airlifting my victim off the mountain would be hugely spectacular. You would first hear the helicopter in the distance, then see a small dot which would get bigger and look for a place to land. The snow would swirl up,

Photo 5. A helicopter rescue dramatized by the dance improvisation about irresponsible skiing

Photo: Anders Larsen

Photo 6. Anders in his element on skis

Photo: Lars Løwe

and it’d be a bit like a movie about Vietnam where the wounded are transported quickly under the rotors and people duck their heads and hurry into the helicopter which flies away again (see Photo 5).

It's something I think about when I ski. So why do I do it then? Well, I've always done it. And as I said, I think it's fun to do some of the things I've always done. It'll come to an end one day; it will for all of us. I've just been to Amager Bakke [dry ski slope] to ski. And I have promised to take my new neighbour there. She says I'm adventurous. That makes me happy (see Photo 6).

What surprises me most in Louise's letter: I thought it was a good letter. It surprised me, Louise, that you were worried about what might come out of the workshop exercises. I thought it looked like you had tried it a thousand times before. I was also surprised at how similar our understandings of the situations were.

The Talking Tree [for description of this group work, see Louise's letter and Figure 1: Collaborative Storytelling Workshops, workshop 4]: I thought again: this is hard. But it's not my responsibility what it can be used for. But Lotte was an excellent tree. Tall, nice-looking girl with a green blouse on. The idea was that we had to go and talk to the tree. We played the scene through twice. I thought the first time was best because I put more into being the retired physicist I was playing. The second time, it became a bit too much like myself (retired economist). Maybe it was because of Louise's cunning way of getting us to talk about our thoughts. I thought it was funny. And the strangest thing is that there are those that believe they can use this for something!

The continuing process: I'm looking forward to our continuing inquiry process. Here, I feel we're actually doing something together. And it's nice that there aren't long questionnaires which is something that people who are hit by Parkinson's also get hit by. You're confronted with about 100 ailments that come with Parkinson's: What's the good of that?

Speak to you soon.

Best wishes

Anders

Lotte's letter

Ballerup, 22 November 2020

Dear Anders and Louise

Here is my letter with reflections from a very exciting process together with nice people. First a few general thoughts. Just think how a tough diagnosis like Parkinson's can bring experiences I'd never dreamed of being a part of. An experience of cohesion and solidarity. We can call it a "community of destiny," even though Parkinson's affects people in very different ways. It's been a really good experience to meet you researchers and all the others. On closer acquaintance, we're not Parkinson's but human beings with many different qualities.

What made the biggest impression on me was meeting other people with Parkinson's and hearing their stories, both more personal stories, and the stories that were told through role play. And seeing how others used dance and movement in their performance. I've started to understand dance and ballet a bit better. In Parkinson's dance classes, I've learned the "old dances" – yes, better late than never! The workshops became easier the more times we met.

The episode with the tree is probably what I've got the clearest memory of. The idea of the tree was as if it were sent from heaven and seemed to me to be the most natural thing in the world. The tree grows near where I live and has partially fallen down. I cycle past it often and look forward to seeing it. I've always liked to think in pictures, and probably still do just as much since I got Parkinson's. In the role play, the dancers dancing around the tree made me happy; it gave me a feeling of not being alone and that life goes on in spite of everything (see Photo 7).

Reading your letter, Louise, was also interesting. Fancy that you were worried about what we'd end up with! It didn't seem like you were worried during the workshops and you got involved in a natural way. You've been involved from the start, where we danced together with Lone [dance teacher].

And the graphic artists, just think what pictures they'll produce! I'm looking forward to seeing and maybe using the finished product [the graphic novel]. Finally I just want to say that I told my husband about the episode and my thoughts about the tree, he probably thinks I'm a bit crazy, he thinks more concretely, but luckily we're all allowed to be different.

Best wishes

Lotte

The Conversation

(For additional information, see photo 8.) As mentioned in the roadmap above, our conversation was based on the question, "What made the biggest impression on each of us when we read each other's letters?" In our reflections after the conversation, we concluded that three themes in the conversation stood out as particularly relevant in highlighting important aspects of what it means for participants to be involved in participatory research. These three themes were also present in the letters– not surprisingly since our conversation constituted a dialogue across the elements in the letters that made the biggest impression on us. Here follows an edited version of the dialogue on each of the three themes. The dialogue has been edited to highlight what we consider to be the most important thematic points.

Photo 7. Anders and Lotte enact the dramatized role play about the tree together with Evy.

Photo: Louise Phillips

Photo 8. Lotte and Louise, in conversation at Louise's home.

Photo: Anders Larsen

Theme 1: Links Between Having Parkinson's, Participating in Parkinson's Dance, and Being a Co-Researcher in a Research Project

This first theme is about a tension that Anders and Lotte experience between meeting each other for Parkinson's dance and in the research project precisely because of the disease and, on the other hand, being part of Parkinson's dance and the research project's workshops as *whole people* who are much more than their illness identity.

Lotte: I think you make an excellent point in your letter, Anders, about making active choices in relation to your life and only choosing the activities that you like—for example, only going to physiotherapy if you like it. That, I think, is the right approach to things. I think it's important to take a stance on what it is that matters to you. That's one of the things you get better at when you get a diagnosis like Parkinson's, I think.

Anders: It's just struck me that when we danced and when we participated in the activities in the workshops as co-researchers, these were both creative things that it's possible to do without being ill.

Louise: Yes, when you participate both in the dance class and in the project, then it's not the disease that's in focus. As you put it so nicely in your letter, Lotte, the other participants in the project are, on closer acquaintance, not Parkinson's but human beings with a lot of qualities. I see a paradox here. You've come together due to an illness and you find a community by virtue of that illness, but, at the same time, you are together as whole people, as human beings. This is something the dance teachers in the project have emphasized; the participants in their dance classes are dancers, not patients. It's the same in our project, where the focus is on dance as an integral part of co-researchers' everyday lives as whole people. Where the co-researchers take part in the co-production of knowledge by virtue of their experiential knowledge of dance as an integral part of their everyday lives.

Anders: But, Louise, what's the connection between what we've been doing and Parkinson's?

Louise: I think that what we've done in the workshops is about looking at Parkinson's dance as part of a whole life, where you're not just a disease and not just someone who goes to Parkinson's dance; you are also a lot of other things. So, we get a holistic picture.

Lotte: And I think that Lone [dance teacher] is really good at that when we're at Parkinson's dance. She doesn't point the finger at you, "you're not able to do it properly." She's really good at looking at us as whole people. I don't feel looked at as a patient. I remember in the beginning, when I went to physiotherapy, the physiotherapist talked about "my patients." That made me think, "patients, patients, patients, patients. I'm not a patient," I said. Well, I did know that I actually am but, all the same, I think of Parkinson's more as a condition. I can't go around for years thinking that I'm ill all the time. I can't connect myself with the fact that now I'm a patient, patient, patient. It's a condition I have to live my life with somehow or another.

Anders: That's very wise, Lotte. It's apt to talk about a condition rather than a disease. It represents a paradigm shift. An illness is something that passes. That's not the case with Parkinson's. Parkinson's doesn't go away.

Louise: Yes. You also write, Lotte, that the diagnosis actually opens up possibilities because it gives you the opportunity to go to Parkinson's dance and to be part of a research project—opportunities you otherwise wouldn't have had.

Lotte: I don't know if I want to say that it's a paradox, but, even though I say that I don't feel like a patient, I still have a sense of solidarity, and I think it's nice to meet other people who are in the same life situation. Or rather, it isn't necessarily the same but as a patient, you can have the same problems.

Louise: That makes me think about what you write in your letter, Lotte, about what it's like to take part both in Parkinson's dance and in the project where you gain the feeling that you're not alone and life goes on.

Theme 2: What Happens in the Workshops When You Meet One Another as Whole People

This theme is about *specifically how* Anders and Lotte experience that they participate in the research project's workshops as whole people who are moved by the participants' stories about Parkinson's dance, and about how Louise realizes that Anders and Lotte's experiences are in line with her own wishes for the workshops. The Parkinson's dance setting contributes to trust, security, feelings of community, and joy (Christensen-Strynø et al., 2021; Christensen-Strynø, Frølunde, et al., in press; Christensen-Strynø, Phillips, et al., in press; Frølunde et al., in press; Houston, 2019), and the same applies to the workshop setting.

Lotte: In the workshops, there have been good opportunities to get to know each other better and do some interesting things.

Anders: When we came, we had to do something, we were put to work. It wasn't like we were sat down and asked to "tell us how we feel."

Louise: So that means that the holistic orientation of the workshops, rather than a narrow focus on illness, has made it possible to get engaged and get something out of it?

Anders: Definitely.

Lotte: Absolutely.

Lotte: I also know the rule of thumb that it's Louise's cunning way of getting us to talk about our thoughts! But now that we've talked about how we're very happy with Lone [dance teacher], I think you should also be praised for having the same approach, Louise, and your colleagues have also done it in a very good way—you started by dancing and joining in our dance class.

Louise: Thank you, it's certainly important for us that we take it seriously that we're supposed to be doing research *with* people and not focusing narrowly on disease or doing traditional research *about* people. The idea is to spend time getting to know each other and building warm, caring relationships as a platform for learning from each other. This is a kind of relational ethics. It's you who have the experience-based knowledge and expertise. We wanted the workshops to be a place where this experiential knowledge came into play in creative processes where we all learned from each other by expressing ourselves physically and artistically in collaborative writing, dramatized role play, and dance improvisation. For me, there is uncertainty about the results when we use arts-based methods in processes of co-creation: they are a product of ongoing creative processes that everyone participates in and no one can or should fully control. You say, Lotte, that you get the feeling that you are not alone and that life goes on in spite of things, right? Is this what you get out of participating, and therefore a kind of learning and a kind of result?

Lotte: Yeah, I do think in a way it is. I'd never tried it before, and, as I say, even if you're ill, you can still learn something new and try something new. Fortunately. So, it's not as if everything just stops! So, yes, when you try to put on your positive glasses, it becomes a positive experience. You can have positive experiences and do something that makes you happy, even when you're ill. And I don't know the world of research at all, but I think it became a bit easier to do the different things in the workshops, the more times we took part.

Anders: I think what we did in the end with the tree, I wouldn't have been able to do it the first time. We'd got to know each other and had been in the workshop setting before where we'd done different creative exercises. I remember the workshop with the tree as one of the most fun things I've done in years.

Louise: Why was it fun?

Anders: I think the role play about the tree was the exercise that was the most successful and important for the project. This was because it was somehow more connected to what we thought the workshops were meant to be about. And someone said that our role play would be of use in developing the graphic novel. I was glad someone said it would be of use! And when we came out and talked to you, Lotte, when you played the tree, we had the framework for it and just had to formulate what we wanted to say.

Lotte: Yes, it fell into place. I can't stand going around thinking black and negative thoughts, I just can't. I think the tree exercise was fun because it was a bit of gallows humor, sometimes I'm able to go around and laugh at myself, saying "you old idiot."

Louise: The role-play exercise was based on Lotte's story. It was you, Lotte, who had sent in the story about the tree before the workshop, did you know that, Anders?

Anders: No.

Lotte: It came from the fact that I cycled past it, it was very natural.

Louise: And as you say, you're good at thinking in pictures.

Anders: And it's about making a life as an old person with a new condition to fit with one's previous life.

Louise: Yes, that there's development but also an element of continuity. It also made a big impression on me in your letter, Lotte, where you write about how you thought up the tree story. That you cycled past the tree. I think this illustrates what the project is really about: it's about gaining knowledge that is based on experiences that are rooted in everyday life. The tree story has roots! It’s about living a meaningful life when you have a diagnosis but, at the same time, are a lot of other things. Creativity also plays a role, I think. Parkinson’s dance is creative, and so are the exercises we have worked with in the workshops, they’re arts-based research methods. So, in the workshops as well as at Parkinson’s dance, a forum has been formed for being creative. At the same time, it’s also a question of what it is we’re creating, right? The process is one thing, but what is embodied learning, and do we learn anything? What did it mean for you that we did the different workshop exercises?

Anders: It was very helpful for me personally to enact the skier scene. So, I definitely got something out of it myself. The scene has its roots in the fact that I say I want to keep doing the things I’ve always done and that’s tied to a bit of conflict because those are things that some people think I ought not to be doing anymore. “What if...”. The skier scene was like a way of showing that it’s not that I don’t think about it; it’s not because I don’t care, but, well, I still do it anyway. It could culminate in my skiing into someone, I definitely don’t want to do that!

Lotte: I think all the exercises have been educational and challenging, and I easily jump into them. And I can’t help comparing it with how I also find it challenging to have the diagnosis we have. It’s a challenging source of uncertainty. On the other hand, I think that I was very shy in the past, and the Parkinson’s diagnosis has meant that I have to be more open and honest. Because if others don’t know how you feel, if you go to the doctor or neurologist, then they can’t help you. You have to say, “I need this and that,” or, “I don’t need it.” You need to be more specific and listen to yourself to find out what you need and what or whom you can get help from. It’s kind of been a consequence of, well, that’s just how it is. This is a realization I’ve arrived at.

Anders: Other people may have a self-understanding of being creative and have tried it many times and know within themselves that, “I can figure this out. It’s the sort of thing I can do, it’s my kind of thing.” And I know within myself that it’s not my kind of thing! I’ve never really tried creative processes before and I may also lack the language to explain it, but they don’t come easily to me. Conversely, I’m not so worried that I’m going to make a fool of myself by playing a different role.

Lotte: You are actually very brave. I’m sure it’s a mix of what one has experienced and of learning something new and then you can build on that. I also think that it’s not equally easy for men and women to participate in creative exercises. Yes, we are different.

Theme 3: Relations Between Process and Product

With this final theme, we explore reflections that revolve around relations between the processes of co-production and the outcomes in the form of knowledge and other products that are supposed to come out of the processes. The first reflection is about Louise’s doubts about what would come out of the “skier” and “tree” exercises, and how these doubts stemmed from a sense of responsibility for ensuring that the project produced results that contributed to research *and* would benefit people with Parkinson's. The second reflection is about Anders's uncertainty about what would come out of the workshop exercises.

Louise: Something that's made an impression on me is that you both wrote in your letters that you were surprised that I was a bit anxious and uncertain about the creative exercises in the workshops. I think this uncertainty has to do with the connection between the process and the product, and you, Anders, allude to this in your letter when you write that you're glad it wasn't you who was responsible for what comes out of the process! We have decided what people should do in the different exercises, and we say we'll be co-producing knowledge about Parkinson's dance as part of people's everyday lives. But who is this "we" that I'm referring to? It's certainly not a "we" of equal partners with equal voices and investments in the project! As the university research team, Lisbeth, Maria and I have had the main say in the design of the project and, as facilitators of the workshops, we have tried to create space for you and the other co-researchers' storytelling, not ours, though one of us is a partner to someone with Parkinson's and has been active in the Parkinson's dance movement. What kind of knowledge have we created together in the workshops? And how will we use that knowledge in the project? That's not obvious. My uncertainty is about whether the workshop processes are both meaningful to you and the other co-researchers *and* will end up in concrete products, such as the graphic novel and research articles, so that the project generates the results we have promised.

Lotte: Yeah, is there anyone who can use it for anything at all? I do understand your uncertainty.

Anders: When you sat down and hosted the podcast, [workshop 2] it seemed like it was something you had tried a hundred times before. You sent the signal that we'll all survive [the exercise].

Louise: That's good to hear! I think my uncertainty is linked to it being open-ended. In a research interview, the researcher asks about what she wants to know. In processes of co-production in workshops, you can't control what comes out of them. At the same time, we as researchers promise both our co-researchers and those who are funding the project that important knowledge is going to come out of the project! So, on the one hand, we know we can't control what comes out of the workshops precisely because this is co-production in which we academic researchers do not have full control. And on the other hand, we promise that it's going to be really, really exciting and that we're going to create knowledge that'll contributes both to research and to improving the lives of other people, right?

Anders: I can see that a lot of material was generated [in the interviews in Phase 1], which we had to work with in the workshops.

Lotte: You have to be able to sort through it and find some structure.

Louise: Yes, and when you, Anders, say, "It's good it's not me who's responsible for it," that touches a sore point! I feel I have a responsibility and that's hard. I think one thing is the material we produced because we have to create knowledge that can be used by others, and another thing is the value of the process. What it means to participate in the co-production process itself—that is, what "co-production" in participatory research means for the participants. So, you can measure the success of what we do on the basis of the quality of the material we researchers will analyze and how many articles we get written *or* you can measure it on the basis of what the participants have gained from being part of the process.

Anders: I also think it's important to consider what it means for the knowledge we create in the workshops that we have fun together, and positive experiences with Parkinson's dance are highlighted. This happened in our letters and this conversation too: we talk about the downsides of living with Parkinson's, but we've given the downsides much less space.

Conclusion

Insider Insights into What "Co-Production" Means from Participants' Perspectives

The conversation across the three themes contains what made the biggest impression on us when we had read each other's letters and responded to each other's utterances in the conversation. In this way, the conversation is the last step in a collaborative process in which we have explored what "co-production" in participatory research means through dialogue across personal narratives expressing our experiential, embodied knowledge as co-researchers and as an academic researcher. The first theme is about the relationship between having Parkinson's, participating in Parkinson's dance, and being a co-researcher in a participatory health research project. Therein lies a paradox: you participate as a co-researcher by virtue of having Parkinson's; but, when you participate as a co-researcher, you are involved as a whole person and not as a (sick) patient. This duality also applies to Parkinson's dance: in both Parkinson's dance and participatory research, you can gain a sense of yourself as a whole person. And because the illness serves, in this way, as an entry ticket to Parkinson's dance and the research project's participatory processes, the illness changes character from being understood solely as a limitation restricting your life to also being an opportunity that opens doors to new and meaningful activities. This duality contains a tension on which we reflect in the conversation: between understanding Parkinson's dance and the participatory research project as meaningful activities *and* nonetheless being ambivalent about participating due to a reluctance to be identified with the illness.

The second theme is about *specifically how* the co-researchers experience meeting each other as whole people in the processes of co-production. A key point is that participating as a whole person is predicated on spending a lot of time getting to know each other in the workshops—and, indeed, throughout the project from the researchers' first meeting with the co-researchers at the dance classes. In the workshops themselves, time is also spent getting to know the workshop format. This contributes to mutual trust and a sense of security. So does the physical and social setting—with cake and coffee and friendly chat during the breaks—and the researchers' facilitation. Trust and security build a platform for dialogue in which participants learn from each other's narratives. The arts-based research methods play a special role as they allow for creative and physical expression and embodied aesthetic and affective knowing through creative writing, dancing, and sensing together. Anders and Lotte point out that they would not have been able to do the exercise with the old tree at the first workshop precisely because they first had to get to know each other and the workshop setting. It is central that they make a link between the successful dialogue that takes place in the tree exercise and the joy and humor of the workshop setting.

The third theme is how to understand the connection between the processes of co-production at the collaborative storytelling workshops *and* expectations about the workshop outcomes. Here, we reflect on the tension between the project's emphasis on meaningful relationships in the process itself *and* producing concrete research results and products that reach beyond the people who have participated as co-researchers. The participation of co-researchers as whole people both in Parkinson's dance and in the workshops contributes to mutual care, trust, and joy which provide a platform for creative, embodied knowing in the workshops. But, at the same time, this setting leads to an emphasis on positive experiences and a toning down of negative experiences. This may circumscribe the knowledge we are able to co-create.

Collaborative Autoethnography as a Participatory Method for Investigating Co-Production

By creating a space for dialogue across personal narratives, our collaborative autoethnographic inquiry invokes experiential, embodied, affective, and aesthetic knowing and thus fits and supports the ideal of democratizing knowledge that is a cornerstone of participatory research. Advocates have argued that collaborative autoethnography reduces power inequities by rendering all collaborating writers "vulnerable in sharing their stories" (Lapadat, 2017, p. 599). As pointed out in the introduction, collaborative autoethnographies are typically carried out exclusively by academic researchers and, most often, are not part of participatory research. In this article, we have proposed and illustrated a format for collaborative autoethnography that enables co-researchers outside academia and academic researchers to co-produce experiential, embodied knowledge about what co-production in participatory research means from the participants' perspectives. In working with personal narratives, the illness experiences of co-researchers are treated as sources of knowledge (Jones & Pietilä, 2020), allowing co-researchers to "recover the voices that illness and its treatment often take away" (Frank, 1995, p. xii). Moreover, the idea is not to disseminate "knowledge packages" but to create space for the further dialogic production of knowledge, where the reader "is invited to put themselves in our place" (Bochner & Ellis, 2016, p. 71) and arrive at insights in dialogue between what they read and their existing understandings of doing research and/or living with a chronic disease.

While collaborative autoethnography centers embodied, experiential knowing in line with the goal of democratizing knowledge, we make no claims that voices are articulated and heard on an equal footing. On the contrary, we argue in our introduction that collaborative autoethnographic inquiry represents a way of working reflexively with a relational ethics that stems from recognition of inevitable power dynamics in participatory research. Our inquiry exposes obvious inequities in our engagement and investments. For instance, Louise designed the format, invited the co-researchers to participate, wrote the first draft, translated the draft into English, and took on the “first author” role of liaising with journals and taking charge of the editing process. And, while Louise makes herself vulnerable in telling her personal stories, her contributions are not based on personal experience of Parkinson’s disease, and they are also less substantial than those of Anders and Lotte. This mirrors relations in the overall participatory research project in which Louise and the other university researchers have had the main responsibility for designing and facilitating processes of co-producing experiential knowledge through co-researchers’ storytelling. Moreover, there is a clear tension between writing in line with an expanded understanding of what counts as knowledge and whose knowledge counts *and* complying with the writing conventions and quality criteria of academic journals (Gustafson et al., 2019). For instance, the latter has entailed the inclusion of formulations by Louise in the introduction and conclusion that position the article’s content in relation to the existing research literature and hence privilege the academic research voice. Thus, our collaborative autoethnography illustrates a way of navigating in conditions characterized by a disconnect between the alluring, seductive promise of dialogue across difference *and* its messy complexities in practice.

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Ethics and Consent

All co-researchers gave their full written consent to participation in the research project and to the use of research material in research and research dissemination. Ethics approval from a board of ethics was not required because, in Denmark, it is not customary to obtain formal ethics approval from a board of ethics for qualitative research.

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