

Reflections on the results of a roundtable on creative methods in disabilities research

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Abstract

In these research notes, we present the results of a roundtable and a subsequent process of reflection on the challenges facing researchers in disability studies using creative methods. The roundtable took place at a conference on disability, “Diversity & Belonging: Celebrating Difference” in Athens in 2018. The aim of the roundtable was to explore with other researchers in disability studies the challenges and joys of academic research using creative research methods. Even though the commitment to inclusive research is common in disability studies, the use of creative research methods still feels like pioneering and unconventional. The purpose of the roundtable was to discuss how we can extend the use of creative research methods so that more people can join in research work. In these research notes, we discuss some reflections on the material that came out of our roundtable and from the reflective session we held after the roundtable. From studying these conversations, we identified four insights on the use of creative methods in disability studies: embodiment, discomfort, connection and plurality of voices.

Samenvatting

In deze research notes presenteren we de resultaten van een roundtable en het daaropvolgend proces van reflectie over de uitdagingen van het toepassen van creatieve onderzoeksmethoden in disability studies. De roundtable vond plaats op het disability-gerelateerd congres “Diversity & Belonging: Celebrating Difference” in Athene, 2018. Het doel van de roundtable was om samen met andere onderzoekers in disability studies de obstakels en kansen van creatieve onderzoeksmethoden in academisch onderzoek te verkennen. Hoewel onderzoek steeds meer inclusief vormgegeven wordt voelt het gebruik van creatieve methodes nog steeds aan als pionieren, baanbrekend en onconventioneel. Het doel van de roundtable was om met andere onderzoekers samen te exploreren hoe we het gebruik van creatieve onderzoeksmethoden kunnen uitbreiden zodat meer mensen kunnen meedoen in onderzoek. In het artikel gaan we in op de resultaten van de roundtable en ons reflectieproces daarna. Door deze gesprekken te bestuderen, identificeerden we vier inzichten over het gebruik van creatieve methoden in disability studies onderzoek: rond embodiment, ongemak, verbinding en meervoudigheid van stemmen.

Introduction

Disability Studies

Disability Studies is a field of study with a social justice agenda which aims to improve the lives and opportunities of people with disabilities. It therefore tends to be action-orientated and collaborative in nature. Inclusive research works towards positive change for and with people who are disabled and those who are not. Disability studies is trans-disciplinary in nature so experiential knowledge, co-creation and the involvement of members of the public are essential features of the research process (Groot & Kloosterman, 2009). This involves using existing and innovative inclusive approaches to systematic data collection and dissemination (Brown & Brown, 2003; Hoppe, Schippers & Kool, 2011; Kool & Sergeant, 2020). In a recently developed consensus statement on how to conduct inclusive health research by Frankena and her colleagues (for example, Frankena, 2019), there is an emphasis on the need for the voice of the person with disabilities to be an integral part of the research process.

It may be worth mentioning that in the Netherlands we use the term “people with disabilities” as opposed to “disabled people”. Both are contested terms across the communities of people with disabilities but as we used this phrase at the roundtable, we will continue to use it here.

A research culture of collaborating and innovation

When creating safe spaces for the contribution of people with disabilities in research it is important to create a degree of choice for research participants to contribute in their preferred way. Using creative methods opens up a broad set of choices and a wide field of methods which offer new ways of understanding and accommodating people who may come from different life experience or disciplinary backgrounds (Kara, 2015).

Jones & Leavy define creative and arts-based methods as, “any social research or human inquiry that adapts the tenets of the creative arts as part of the methodology” (2004, in van der Vaart et al., 2018, p. 3). Art genres that might be used are, for example, visual art, performing art, literary art or a combination (Coemans & Hannes, 2017). Until recently, co-researching with people who professionals considered “vulnerable” or having less social power, was often done by working with their narratives, interviewing them, and working with their carers who would attempt to represent their experiences.

Research Notes

In these research notes, we share the learning from a roundtable discussion with other disability studies researchers to find what helps or hinders their use of creative methods in research. Following analysis of the roundtable material/data, we provide evidence of our thought processes which might serve as a precursor towards the advancement of new ideas and discussions in research and practice (Sergeant & Peels, 2018).

Method: Reflecting on creative methods in research before, in and after a roundtable

During the 5th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Europe Congress, “Diversity & Belonging: Celebrating Difference” in Athens in 2018 we organised a roundtable to reflect on the matter of creative methods in research. Twenty congress attendants joined the roundtable. Congress attendees were invited to join the roundtable

based on their interest or experience in arts-based research; we did not select or ask if people were disabled or not. We could hear from their introductions that participants of the roundtable were diverse in background, professional experience and nationality, coming from Canada, Greece, Spain, Belgium, the Netherlands, Singapore and Turkey. Most were working as researchers, some also as music/drama/art therapists and artists. All participants signed an informed consent form that allowed us to use the material the participants shared at the roundtable.

The Wall of Inspiration

To inspire and guide the conversation we used a *wall of inspiration*. This wall allowed us to share elements that progress or hinder the acceptance and use of creative methods in research. The wall of inspiration was designed in a way to accommodate the exchange of ideas. It was accessible for all participants. We asked the participants to write or draw keywords, past experiences, ideas, hopes and disappointments on the inspiration wall. During this process, the participants were invited to discuss, ask questions and share experiences so the wall prompted a community of conversation.

Bicycle as cultural metaphor

We decided to use a simple metaphor of well-known parts of a bicycle, so common in many European countries, since most participants would understand this metaphor and how the different parts of it work.

The pedals (right) represent ways to further creative methods.



The brakes (left) represented factors that either hinder or balance the use and acceptance of creative methods.

The images were pinned to the wall with a blank space between these sides for ideas that don't fit either of these sides.

The roundtable led to a range of *brakes* and *pedals* showing them within a (broader) continuum of methods and paradigms in science and practice (Peels & Sergeant, 2018).

We used the material from the roundtable as a starting point for an inductive thematic analysis with further reflection on the use of creative research methods. This step of reflection was done by us authors a few months after the roundtable through discussion in live meetings and through writing and re-writing together. The reflection brought us in a space somewhat reminiscent of Bakhtin's ideas on dialogic interactions and relationships thus making room for multiple voices and ways of seeing that are unique and different from each other (Robinson, 2012). Differences and contradictions were welcomed as the diversity of the voices added complexity to meaning making together (White, 2015).

Results

From this process of organising the Round Table with over 20 participants, the reflection sessions with authors and the writing and re-writing together, we identified the following insights in the use of creative methods:

1. Embodiment

Precisely because we are never merely objects, but simultaneously living subjects – sensing, moving and experiencing – our materiality makes us open and vulnerable to the world.

(Wehrle, 2020, p. 500)

Discussing this theme of communication brought us to the concept of “embodiment” and how people express their ideas, feelings and stories through their bodies, in various forms, in tangible or visible forms of expression, for example through a self-made photograph, dancing or drawing. Such material constitutes communication and can therefore be considered valuable data.

By using the lived and physical aspects of the body (Wehrle, 2020) to gather data about a story or concept, we allow the richness of data, both cognitive and physical concepts, to enter and extend “the picture” (Kara, 2015). Data are not then seen as isolated items but as intertwining parts of a story. As Hannes has said, “If I had not been there, I would not have told my story like that.” (2019). Embodied knowledge provokes strong responses from both the researcher and the researched and therefore needs outlets, opportunities for sharing. Such emotions can provide “a catalyst for learning beyond traditional, cognitive ways of knowing”, as observed by Lawrence (2008, in van der Vaart et al., 2018) and lead to stories not yet told or heard (Jensen & Penman, 2018). A more complete, richer story then is the subject and contribution of the research.

Creative methods stimulate not only the dialogue between researcher and research participants but the whole data gathering process becomes as a multisensory experience. One can appreciate contextual elements like the space where the data gathering takes place, the choices of people to include or exclude elements of their own story and the responsibility of the participants to be part of the reflections and analyses made. One of the participants of the roundtable wrote it allows “new ways to see”. Other participants wrote that “including emotions” or “intuition” was important in promoting creative methods in academic research.

2. Uneasiness with messiness

Data gathered by creative methods are far from “separate things”. They are relational, connected with emotions, narratives and the varied, complex circumstances of both the researcher and the researched. The concept of “necessary distance” between the researcher and data is challenged. Without the relational context of communicator and listener there is no intimate exchange and therefore new learning. This may cause uneasiness and dilemmas for people used to traditional methodological assumptions of researchers being separate from the process. But in inclusive arts-based research, researchers and their research practices are rightly changed by the feedback from the research participants. Analysing their stories may touch the researchers and highlight painful aspects of their own lives.

On the inspiration wall someone wrote, “level of confidence!” (on the brakes side); “action-and change-oriented orientation” (on the pedal-side). In the analytic processes, we discussed how we too recognised the need for more confidence at times to become action-and-change oriented when promoting arts-based research with community members.

Poetry can also work in powerful and meaningful ways but can also confront the researcher, provoke emotions and, methodologically, create uncertain about how to treat and whether to attempt to interpret the data or let it speak for itself. This is a highly political matter given the history of professionals speaking on behalf of population groups often resulting in misinterpretation of experience and need.

Participants in the roundtable noted the struggle they experienced in their work in terms of getting projects funded and the research results published given how many journals still subscribe to very specific academic conventions (van der Vaart et al., 2018). People also raised issues of research ethics committees whose members were not familiar with arts-based research or were concerned about participant confidentiality. The words of Tina Cook (2009, p.11) summarise the uneasiness with messiness, “The messy area is a tough place to be”. But we also agree there is no other way if we want to ensure more disabled research participants voices are heard to promote better understanding of experience. Grappling with journals and ethics committees is part of the struggle necessary to ensure broader dissemination of research work.

3. Connection

This theme was highlighted in several of the posts on the “pedals” side of the inspiration wall: “empathy and love” or “producing not to score brownie points”. Creative methods evoke closer connections between researchers and research participants and more quickly than conventional methods. Moreover, trends in public sector research expect not only accessibility in research methods but inclusivity in which there is an expectation that researchers and research participants will collaboratively analyse the data. The research relationship is a connection that requires mutual trust, respect, interest and an investment in the cooperation. It involves all parties being invested in time, patience and openness of mind to engage in the art form like dance, theatre or other genres. This investment, however, carries with it uncertainty: as a researcher or as a research participant, you don’t know what the participation will bring you. Professionals have to suspend their expertise and foreground that of their research participants (Anderson, 1992).

4. Plurality of voices

Diverse methods of gathering data expand the possibility of finding different knowledge. Creative methods offer a similar potential to inclusive research as they invite different voices and point of views to build a better and more overarching understanding of people’s lives. Openness and clarity about each other’s roles, about relationships and the timeframe are important (Nind, 2014). Time is needed to get to know each other well, to be able to be mutually vulnerable. One of the participants of the roundtable sketched glasses with the writing: “care, politics, research, arts/design”. It is like wearing glasses with different purposes and means in sight. The plurality of voices requires creative approaches to research but also the need for safe spaces to conduct research. While many research

participants are vocal and articulate in identifying their views, others struggle to find a voice or a means of expressing themselves so researchers have a responsibility to research and co-develop what creative methods are suitable for hearing people with disabilities.

Concluding thoughts

A growing preoccupation in the field of Disability Studies is how to gain a clear understanding of people's wishes, hopes and anxieties (Brown & Brown, 2009; Schippers, 2010; Brown & Faragher, 2014). Exploration of people's wishes, their thoughts and needs as expressed by them is always important and sometimes a challenge if individuals have sensory disabilities which impact on responding to and expressing language. These are challenges researchers need to address with their research participants to ensure the needs of people with differing disabilities are heard.

The field of literary and arts-based research is a wide and established part of the qualitative research field. Although the credibility and acceptance of creative methods in mainstream research is now widely accepted, the results of our process however lead to the conclusion that it still proves a challenge to researchers. While most of the notes on the inspiration wall in the roundtable highlighted the positive aspects of creative methods, many researchers identified difficulties in progressing creative methods of research with people with disabilities.

These research notes summarise reflections from researchers in disability studies who had experience of or were considering the use of creative research methods which promote inclusivity with people with disabilities. We have found it helpful to document creative methods using fieldnotes or an audit trail to analyse what happens during the research process. Awareness of the process and inclusion of all researchers and participants require preparation, training and support before, during and after the process. But at the same time, protocols don't precede but grow out of the moment of engagement through collaboration, transparency in research relationships (Kuntz, 2010).

These research notes, it made us think back with pleasure to the process of working together with so many people from different backgrounds. We'd like to extend therefore our gratitude to all those involved.

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