“It is…, it stands for…, it shows…”: arts-based representations in data generation and analysis

Abstract

Arts-based approaches are employed because they allow researchers get closer to the participants’ experiences and emotions, because they help participants express experiences differently, and because they support participants’ processes of reflection and meaning-making. The benefits of arts-based approaches are therefore undisputed and often summarised as enabling richer, deeper data.

In my contribution, I draw on my research into the lived experience of chronic illnesses and disabilities to highlight how two kinds of arts-based work leads to different forms and results in data and furthermore, how arts-based data generation lends itself to an arts-based analytical process.

Key words

metaphors, Lego, identity box, chronic illness, disability, fibromyalgia, arts-based analysis

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Research Methods, and is currently authoring *How to Make the Most of Your Research Journal*. Nicole's research interests relate to physical and material representations and metaphors, the generation of knowledge and, more generally, research methods and approaches to explore identity and body work, as well as to advance learning and teaching within higher education. She tweets as @ncjbrown, @FibroIdentity and @AbleismAcademia

Introduction

The benefits of arts-based approaches are widely reported, even though arts-based research may only just start to emerge in some disciplinary contexts (Fraser and al Sayah, 2011). Arts-based approaches tend to be employed in social science research because they help gain "new insights; describe, explore, discover, problem-solve; forge micro-macro connections; raise awareness and empathy; unsettle stereotypes, challenge dominant ideologies and include marginalized voices and perspectives" (adapted from Leavy, 2018:9f) and they enable a "remaking the social world" (Barone and Eisner, 2012:27). Arts-based approaches have been found to be particularly helpful in research with sensitive or emotive topics or in research with participants from different cultural or linguistic backgrounds, participants who may be children or who may have cognitive impairments (Kara, 2015).
In short, arts-based approaches allow researchers get closer to the participants' experiences and emotions, because they help participants express experiences differently, and because they support participants' processes of reflection and meaning-making. Often, these benefits are summarised as enabling richer, deeper data (Horgan, 2017).

In my contribution, I draw on my research into the lived experience of chronic illnesses and disabilities to highlight how two kinds of arts-based work led to different forms and results

in data and furthermore, how arts-based data generation lends itself to an arts-based analytical process. I argue, that the data is not necessarily richer or deeper, but different, which makes it insightful and exciting. I commence my chapter with an outline of the theory underpinning the work with metaphorical representations and object-work, which leads into an introduction to the context of my research with examples of data generated by participants: an identity box, a canvas and a LEGO® model. I demonstrate how these representations in combination with conversations with participants lead to embodied, visceral responses, which, in turn and quite automatically, lend themselves to an arts-based approach to analysis. I show the benefits for researchers as well as participants and the wider society, when it comes to understanding and sharing experiences. I conclude with practical strategies and wider consideration of applicability of arts-based stance in data generation and analysis in healthcare research.

Theoretical underpinning to metaphorical representations

Research is often seen as too distanced and remote from the physical bodily experience instead of seeking to insert the body into the theoretical understanding (Ellingson, 2017). Ultimately, an embodied approach (Ellingson, 2017) is needed that transcends "dualistic legacies of the past" (Williams and Bendelow, 1998:3) and that puts "minds back into bodies, bodies back into society and society back into the body" (Williams and Bendelow, 1998:3,209). According to recent discourses within research theory and practice, the answer is to transcend disciplinary boundaries, to develop multimodal forms of enquiry (Dicks, 2014; Hurdley and Dicks, 2011; Jewitt et al., 2016), and to combine sensory and visual ethnography (Pink, 2013, 2015) with creative research methods (Kara, 2015). Despite their very individual and individualised designs and philosophies, all of these approaches are

founded on three basic principles (see also Brown, 2019a, 2020; Leigh and Brown, 2021). The first premise is that human language is limited and limiting, especially when individuals try to explain and describe sensations, such as pain, or other embodied and bodily experiences (Scarry, 1985; Sontag, 2003; Eccleston, 2016). Secondly and related to the limitation of language, human understanding and experiences are fundamentally embodied (Finlay, 2015). Babies, toddlers and children experience being lifted, held and hugged, and use their whole bodies to explore new objects before they are able to put these experiences into words. And thirdly, because of the embodiedness of human understanding and the arbitrariness of language, humans turn to metaphorical expressions and forms of communication in order to compensate (Lakoff and Johnson, 2003; McKiernan, 2018). The aim of the creative, sensory and multimodal methods is to overcome these challenges to research by drawing on creativity and arts. Existing research into lived experiences include the process of creating representations through the use of Lego (Gauntlett, 2007) or sandboxes (Mannay and Edwards, 2013), the introduction of art workshops (Tarr et al., 2018) or collaborations between artists and research participants (Bartlett, 2015).

Like many frameworks and paradigms arts-based research has also evolved over the course of time and so cannot be neatly packaged into one category. Depending on the focus of the enquiry, the aim of the research and the positionality of the artist-practitioner-researcher there is "arts-inquiring pedagogy, arts-based inquiry, arts-informed inquiry, arts-informing inquiry, arts-engaging inquiry, and arts-related evaluation" (Savin-Baden and Wimpenny, 2014:5). In all of these forms of arts-based enquiries, the arts are used to "raise significant questions and engender conversations; to capture meanings; to diversify the pantry of methods that researchers can use to address the problems they care about; and to

contribute to human understanding" (Barone and Eisner, 2012:164-172). Within the context of seeking understanding of pain experiences, but also to represent those experiences and thereby to create outputs that would challenge existing social structures "turning to the arts and literature is often recommended as a strategy" (Williams and Bendelow, 1998; Bendelow, 2000:64). More specifically, according to Leavy (2015) employing arts-based research helps

> to provide new insights and learning; to describe, explore, discover, problem-solve; to forge micro-macro connections; to engage holistically; to be evocative and provocative; to raise awareness and empathy; to unsettle stereotypes, challenge dominant ideologies, and include marginalized voices and perspectives; and to open up avenues for public scholarship, usefulness and social justice (Leavy, 2015:21-27).

Mills (2000), Bochner and Ellis (2016) and Denzin (2016) all talk about sociological research needing to connect the personal with the historical and the social. In the case of autoethnographies, the personal relates to the personal of the researcher, thus the researcher's own experiences. Arts-based researchers suggest that such connections are possible and more easily achievable through the use of arts, as the arts express and foster emotions and emotional responses. Through personally touching audiences it is possible to draw in individuals, thus to raise awareness of wider social and societal issues, and to cause action.

Research context

For the last five years, I have researched the lived experiences of staff and doctoral students with chronic illnesses, disabilities and/or neurodiversity. In this chapter, I will refer to my doctoral research "The 'I' in fibromyalgia: the construction of academic identity under the influence of fibromyalgia" (Brown, 2018a, 2018b, 2019a, 2020) and my research "Ableism in

academia: developing institutional approaches to inclusivity" (Brown, 2021; Brown and Leigh, 2020), which was funded through the Grand Challenges funding scheme at University College London. As full details are available elsewhere, I will only provide some basic details to offer an insight into the research contexts in the following.

The 'I' in fibromyalgia: the construction of academic identity under the influence of fibromyalgia

Fibromyalgia is a contested condition (Ehrlich, 2003; Wolfe, 2009) that is characterised by persistent, wide-spread pain, fatigue, sleep disturbances, cognitive dysfunctions, increased sensitivity and psychological disorders (White and Harth, 2001). The premise of this research was that fibromyalgia in its complexity and contested nature would impact academic identity, especially because of the symptoms such as memory and word retrieval or sequencing issues associated with cognitive dysfunctions. The overarching research questions were formulated as 1.) What is the relationship between fibromyalgia and academic identity? and 2.) Can creative methods help explore changeable phenomena?. Data collection methods included semi-structured, one-to-one interviews, the generation of timelines and identity boxes, the participation in an online Facebook group discussion and the creation and employment of additional and alternative representations. For the analysis in this chapter, I only focus on the identity boxes project, for which participants were asked to collect objects in response to questions and to place them in their chosen box. The participants were then required to take a photograph of the objects in the box and send an email with a brief outline of the objects in the box and what they represented. A new question was only released once the previous question had been answered. In total, there

were five questions to be answered: Who are you? What affects you? How do others see you? What role does fibromyalgia play? What is life with fibromyalgia like?

Figure 1 is an example of an answer to the question What role does fibromyalgia play? as provided by Claire (pseudonym).

I have **a broken watch**, which depicts the time that has been stolen from me; the inability to move forward in my life. I have a broken piece of tree that represents my family which shows some parts have been broken and some have actually been severed because of my pain medication. I have been prescribed marijuana.

I have **a nail**. This represents the iron will that I have to fight this disease as hard as I can. It also represents the fact that I have to do it pretty much alone, as I am the only person that can fix me. But as strong as I am, I am bending. The last thing I have is a toilet paper roll. This represents how empty, hollow and lonely this fight leaves me feeling most of the time.

Figure 1: Claire's response to the question "What role does fibromyalgia play?"

Ableism in academia: developing institutional approaches to inclusivity

This research followed on from and built on my fibromyalgia work. One of the outcomes of the fibromyalgia research was the recognition that academics constantly feel under

pressure to perform, to be effective and productive and that they consistently compare themselves to the ideal standards of an able-bodied academic. The overarching research questions for this project therefore were 1.) How do students and academic staff experience ableism in academia?, 2.) Which strategies can be employed to alleviate feelings of exclusion? and 3.) How and in how far does academia need to change to become more inclusive?. Data was gathered via a survey with closed and open-ended questions with 300 respondents, semi-structured, one-to-one interviews and the creation of representations in an arts-based workshop. My focus in this chapter is on the representations. Participants were offered a wide range of arts and craft materials, such as paints, canvases, collage materials and glue, with which their representations of the experience of disability, chronic illness and/or neurodiversity would be created. In addition to traditional arts and craft materials, I also offered LEGO® bricks as a medium for creations. Figures 2 and 3 are representations created in the workshop. The LEGO® model in Figure 2 highlights the isolation experienced by those who are disabled, chronically ill and/or neurodiverse, whereas the work in progress on the canvas in Figure 3 focuses on the career trajectory and its disruptions and interruptions due to disability, chronic illness and/or neurodiversity.

Figure 2: Being disabled, chronically ill and/or neurodiverse in academia is being isolated

Figure 3: Work in progress - disability, chronic illness and/or neurodiversity "interrupts" career trajectories

Analysing data from arts-based data collection methods

Qualitative data analysis is more than merely following specific steps to achieve meaning. Indeed, analysis is a craft that requires "reading beyond data" (James, 2013:574) and falling back upon "the repertoire of implicit knowledge that researchers themselves possess" (James, 2013:574). Therefore, data analysis can never be an objective process of having themes "emerge". It is a very subjective, personal and active process of the researcher making sense of data and pulling out specific themes and meanings (Morgan, 2018). The researcher is "a trickster, a person who is a jack-of-all-trades, a person who can fix things with the materials that are at hand" (Denzin, 2016:36), and thus consciously manipulates, assembles and reassembles data (Deleuze and Guattari, 2016). As researchers we let data speak and grab our attention, and then follow our "gut feelings" in tending to those "hot spots" (MacLure, 2011). The conventional approach to data analysis using iterative, inductive, semantic thematic analysis (Braun and Clarke, 2006, 2019) allowed for the generation of specific themes, such as experiences of isolation or disruptions and the management of public and private selves. However, the conventional analysis process through coding and identifying themes is limiting and limited, as it does not necessarily allow for a good representation of experiences. In conventional analysis we attempt to put into words what participants have expressed metaphorically through objects. With this in mind, a second layer of analysis is required. Bearing in mind the key elements of good research – transparency, criticality and reflexivity (see Brown, 2019a, 2020; Leigh and Brown, 2021) – we can therefore combine conventional qualitative data analysis with a more creative approach to making sense of data. Whilst the individual photographs and objects are always very specific to individuals, there are commonalities expressed around

the participants' experiences of life with disabilities, chronic illnesses and/or neurodiversities. In the case of the fibromyalgia research, the identity box project lent itself to a more creative approach towards analysis in addition to the traditional textual analysis: the illustrated poem "I need duvet days" (see Leigh and Brown, 2021) and the art installation "Peace Treaty" (see Brown, 2019a).

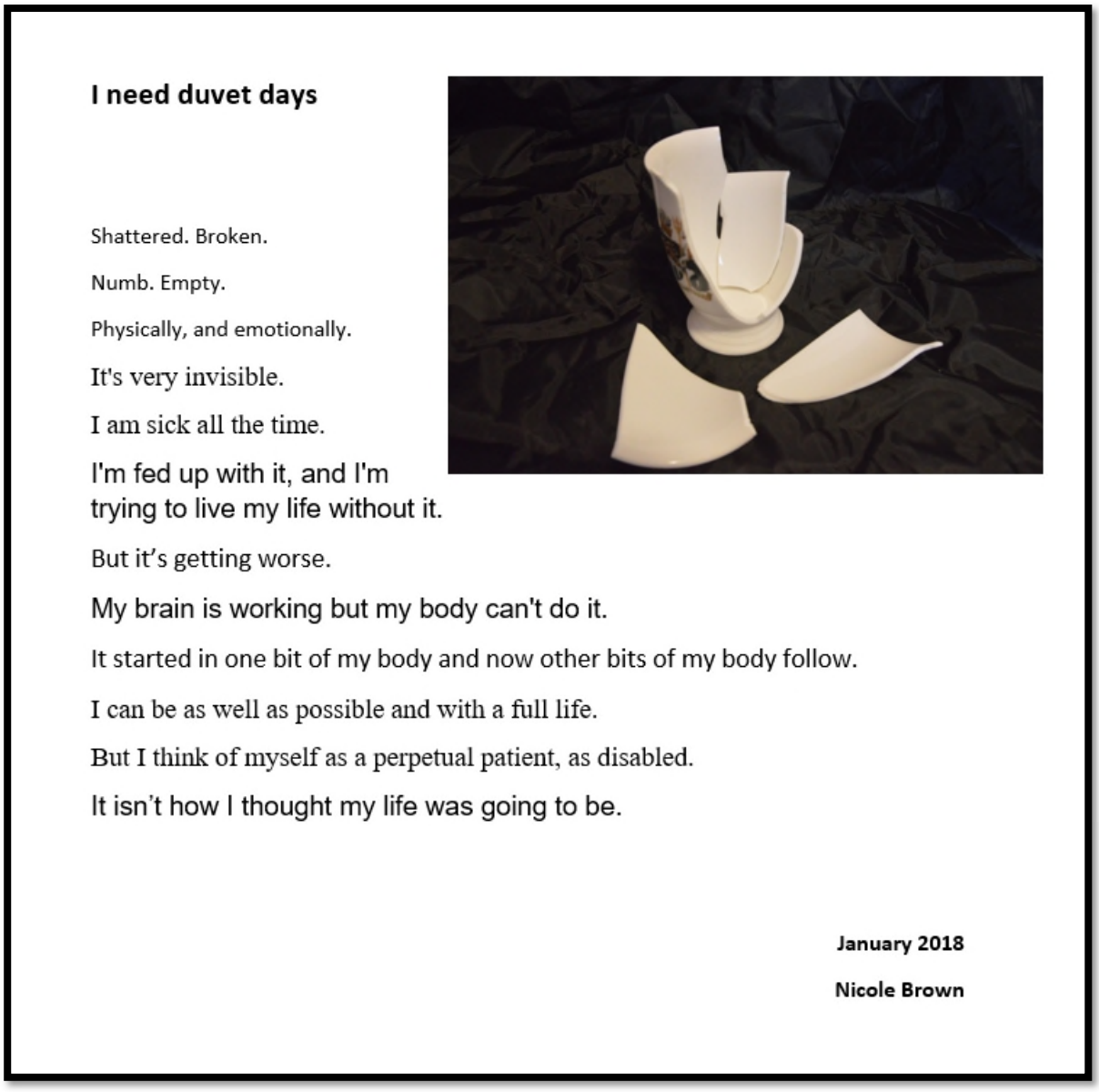

Figure 4: Illustrated poem "I need duvet days"

Figure 5: Art installation "Peace Treaty"

The analytical process that led to the creation of these two representations followed the analytical principles of Embodied Inquiry. The main premises of embodied analysis are that the researcher plays an active role in making sense of data and what the data represent and

that physical experiences cannot be excluded from the research process. In everyday life, we often experience symptoms in response to environmental and contextual influences: our breathing and heart rate quicken, when we are scared or angry; we feel headaches coming, when we are overwhelmed. These automatic, bodily responses also occur during the research process, but are often ignored or suppressed. Embodied Inquiry, by contrast, asks the researcher to listen and respond to their bodies, thus to become more consciously aware of their bodily responses. Figure 6 is an excerpt of a written conversation between myself, Nicole, and Claire, the participant, whose identity box has been presented in Figure 1. Initially, Claire and I had scheduled a video-conference call to hold the interview (Brown, 2018b), but due to issues with the internet connection at Claire's end, we were forced to abandon the conversation and ended up messaging each other. The excerpt relates to the section in the written conversation, where Claire and I talk about her having included the broken watch and the nail.

Nicole: Can I ask you about the marijuana prescription you mentioned?

Claire: Yes, it was because I was in so much pain that I could not see a life without pain. And I could not face going into more pain as a daily thing. I had seriously considered giving everything up and taking my life so that I would not have any more blue, and then I tried marijuana. I'm glad I tried it before I did something drastic. It was a pretty messed up time in my life. […] There are 2 family members who will no longer associate with me due to my marijuana use. My eldest daughter and her husband have gone so far as to try and stage an intervention. I use MM (medical marijuana) because I can not take OTC (over the counter) pain meds, any opioid based medication, and gabapentin or member of its drug class, which leaves very little that I can take. My Dr here has given me a prescription to use it and it has helped with pain, anxiousness, sleep pattern and, surprise, surprise, it's even slowed down the brain fog somewhat.

Nicole: It must be upsetting to think that this has affected relationships. But that aside, how do you feel about taking drugs?

Claire: I feel like I'm taking my prescription just like any other person.

Nicole: Would you ever have thought that you would do drugs like that?

Claire: No. As a paramedic, I hardly even drank! And now I eat pot brownies! Wow, that's a totally different me. But it works, so I will continue.

Figure 6: Excerpt of written conversation between Nicole and Claire

After the interview with Claire, I had written the following reflections in my journal:

> Video conferencing did not work as the speed of the internet was too slow. This meant we had to type our interview as a messenging dialogue. The benefit is that I was able to go back to questions as they were there written down, but her answers were slower, more stilted.
> Also, it was difficult to know whether she was writing and adding more ideas or waiting for my input or if she was distracted with something. From our chat I know that she was fully focussed on the interview and she had the box with her. But the importance of the visual cues really came out. Was she thinking? Did she not get the message?
> Also, in the skype interview I can just keep a pause and allow for more thinking time, but in the written version this didn't work because Claire couldn't see me, so she was missing the visual, nonverbal clues, too.
> The other thing is the emotional content I am reading into the writing.
> When I read what Claire was writing, I heard it as spoken in a voice, not my voice, but obviously not her voice either. I am not sure whose voice this was. It was a female voice, probably younger than Claire is. But this just shows the kind

> of interpretation that happens at that stage already. I heard emphases, that - in hindsight - aren't actually there.
> Through this interview I realised how much the pitch and tone are important, and need to be analysed alongside the pictures. Also, I now realise that I actually hear voices a lot. Even when reading emails, I hear voices. Some of them may be close to the writers' actual voices but others cannot be because I don't know the people well enough. But ultimately, this must distort the process all the time!!

At the time, in February 2017, I was worried about the "distortions" and "early interpretations". However, being attuned to these processes so overtly and consciously meant that I could tap into my bodily responses for the analytical process. The artistic analysis presented in Figures 4 and 5 are in practice nothing else than representations of where I truly *listened* to transcripts, not just listened to hear participants' words, but listened viscerally using my body as a tool and gauge. Creating the illustrated poem and the art installation therefore was an embodied activity aiming at eliciting a similar embodied response in an audience. In practice, I merely collated objects represented within participants' identity boxes and lines from interview transcripts that spoke to me and I rearranged those in what felt like a meaningful way. I was that "jack-of-all-trades" (Denzin, 2016:36) who consciously manipulated, assembled and reassembled data (Deleuze and Guattari, 2016). The result of that process is a conglomeration and reinterpretation of participants' experiences.

Moral and ethical consequences of using arts-based methods

When carrying out research using arts-based approaches for data generation and analysis, there are moral and ethical considerations to be taken into account that differ from conventional research. The first concern is how to deal with data. Employing the methods that result in non-linear and non-uniform data means that data transcend traditional

boundaries and therefore work on a literary level, a musical level or an artistic level. Are we then supposed to engage with that data in the respective form and provide a literary, musical or artistic analysis and evaluation? Or can we consider that data as a piece of art and simply let it work its evocative function?

Linked to this first concern, we also have to start asking questions relating to ownership. As the researcher of this project *I* am exploring participants' experiences. *I* formulated the research questions, and *I* developed the research approach and design using the creative, artistic forms of expression in this context. *I* own the research process; *I* own the research. However, the participants created their personal forms of communication and representations of their experiences. They did so in response to my questions, but it is after all *their* work, so they should effectively own the pieces. In practice, during the course of research projects participants in a way relinquish their right to the ownership of their outputs. This is not because I am not willing to share their work and give them credit, where credit is due. This is because research participants may not necessarily have chosen to disclose their conditions and so, their representations need to remain anonymous. Interestingly, debates around this kind of ownership within research most often occurs when artistic outputs or works of arts are produced. Interview transcripts or survey responses are not considered in this same way, although they, too, are forms of expression and communication. There are researchers who offer participants the opportunity to go back over statements, which are intended for use in publications in order to identify whether the participants would be comfortable with that specific section being used. In a way, therefore, there is an implicit understanding that the participant owns that transcript. These forms of participatory decision-making are, however, rare, and in most social sciences

research the power differential between participants and researchers characterises the relationships between the stakeholders. For me, the question of ownership is key to the relationship I have built with the participants. I am under no illusion that I have been able to fully tear down the power differential between me, as the researcher, and my research participants. However, having assumed the role of the data traveller (Brinkmann and Kvale, 2015), having collaborated on the representations and having engaged jointly in the meaning-making processes, I do feel that I am more than the objective researcher in that relationship. I consider the participants' original creations as their work, but I am taking the liberty to use their work, recreate, modify and mould it to become a representation of the bigger picture. After all, I have been entrusted with personal stories and narratives and I feel obliged to act on those.

A third concern is linked to and comes out of considerations around ownership, and it relates to anonymity and recognisability. As described above, participants own their pieces of art and artistic outputs, just as they own the transcript. With transcripts, we routinely anonymise and pseudonymise participants and ensure that they are not recognisable from their personal names and stories. Where the pieces of arts are concerned the question of ownership and crediting the creator may hinder that process. Participants' contributions may be so personal that they can be recognised from the backgrounds and surroundings in photographs, or the objects they use are so personal that others could potentially identify individuals from those objects. For example, Claire's identity box in Figure 1 includes her marriage certificate. At the same time, however, contributions and creations are so personal that the participants may feel proud of them and may want to have their work publicly recognised as theirs. Negotiating creativity in this sense is a balancing act of offering details,

opening up deeper information and experiences whilst at the same time protecting individuals' identities and emotions.

Finally, and probably most crucially, there is a concern around the relevance and impact of creative methods of expression. Scholars recognise limitations of existing research methods and methodologies and therefore call for more embodied and sensory approaches to research. Within the current research methodology discourse, data from creative methods is considered as "richer" and "deeper", although we do not have any means of truly making this judgment. In reality, the data is different; it is not better, deeper, richer; it is different because it draws on the arts, which function by being evocative and provocative, thus by creating emotional responses. To illustrate this point, I would like to refer to an example from the fibromyalgia research. In response to what fibromyalgia feels like, Amy (pseudonym) likened fibromyalgia to a scratchy, horrible cactus, to which we would not want to go near because of the needles and spikes sticking out:

> A cactus.
> In terms of it being really scratchy and horrible, and not wanting to go near it, all those little things sticking out. That's what made me think of it. And because of sensations, to feel like a cactus scratching you, and that's I guess what made me think of it.
>
> Amy

As readers of this excerpt, we can make sense of Amy's experience, cerebrally process what she is trying to tell us and so, we can cognitively understand. If, however, this excerpt is presented together with an image, our perception and understanding is altered drastically. The choice of representation and the kind of cactus we use is deeply relevant:

Figure 7: Three different images of cacti

It is probably easier to identify with the negative, prickly sensation Amy describes, when we look at the first of the three images, as the other two images demonstrate an element of beauty that is not described in Amy's statement. We are physically and emotionally responding to the image. Is the data richer or deeper? Or are the visuals merely tapping into our own memories evoking experiences of when we once touched a cactus and felt the sharp spikes getting caught in the skin of our fingers? The visual representation involves us emotionally effecting bodily and embodied responses. This non-linearity is obviously not easy to capture in traditionally conventional forms of representation, such as this thesis or publications like journal articles and books. Cerebrally, emotionally and academically, scholars agree on the use of the creative and arts-based forms, but in practical terms, our research outputs are largely gauged and driven by publishers' demands and our need to produce internationally recognised academic artefacts that can be entered to assessment exercises like the UK's research excellent framework. This pressure from external forces leads to creative methods of expression being recognised and accepted only within the context of data collection to "deepen" the interview data, to elicit experiences, to

encourage memories and thoughts and thus to promote or stimulate conversations in social science research.

Practical considerations for using arts-based approaches in research

In the previous section regarding moral and ethical consequences of using arts-based approaches in research I have already hinted at some practical considerations, too.

Within the scholarly community, arts-based approaches become more and more recognised as powerful tools for and of inquiry. This is because the artistic expressions and creations enable different forms of communication, which are often more natural for individuals. This is particularly true in the 21st century, which is characterised by significant use of smartphones and social media platforms that function on the basis of visual communication, either per se or in conjunction with textual inputs. Where once photography was a hobby for a few privileged individuals, it is now part and parcel of creating memories and identities. However, the role and position of arts-based approaches within academia is ambiguous, as the publications process highlights. Whilst the use of arts-based approaches, such as photo-elicitation (Orr and Phoenix, 2015) or photovoice (Guell and Ogilvie, 2015), for example, are becoming more mainstream, the way that research is reported is not. The visual data and representations are used as a way *into* the interviews and conversations rather than as data *per se*. As a consequence, "the output or creation is not used" (Brown, 2019b:1).

Another important aspect when working with arts-based approaches relates to participation. Some participants do not feel comfortable creating artistic representations or

working with specific media and materials. For some, materials such as glue, paints and glitter are uncomfortable to touch, for others they are too much of a reminder of a child's play, while others still worry about the beauty or aesthetic perfection of their creation. The use of LEGO® in these contexts is advantageous because many people do not associate LEGO® with an artistic form of creation that would need to meet criteria of aesthetic perfection. At the same time, the material of the plastic bricks tends to be largely acceptable and tolerable even for individuals with sensory processing difficulties, whilst for example the sand of sandboxing approaches is less widely amenable.

In addition to managing materials and objects, researchers employing arts-based approaches need to be aware of additional levels of intensity that are reached through this kind of reflective work. Creative methods help research participants reflect through narrowing down their experiences to an essence and then subsequently in the conversations elaborate to explore the details of these experiences. These embodied, material representations of experiences resulted in deeper reflections than the surface reflections commonly observed in the reflective practices of diaries and logs (Fook et al., 2006). This then leads to deeper emotional engagement on the part of participants than an interview on its own would lead to. It is therefore particularly important for researchers to be prepared to provide the relevant support for their research participants. Although the research process may be experienced as cathartic or therapeutic, it is not, cannot and should not ever replace therapy.

Chapter summary

This chapter:

- outlined the theoretical frameworks underpinning the use of arts-based approaches to research
- highlighted how art-based approaches to research reflect the metaphorical and embodied nature of human understanding
- offered an insight into two research contexts that employed arts-based approaches
- presented how data from arts-based approaches may be analysed
- discussed moral and ethical consequences as well as practical considerations relating to the use of arts-based approaches in research

Learning opportunity

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