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Identity boxes: using materials and metaphors to elicit experiences

This paper considers the use of identity boxes as a data collection method to elicit experiences. Participants were asked to respond to questions using objects to represent their answers. The rationale for using identity boxes was to allow for a more embodied, less textual approach. The identity boxes were then also used to create an artistic installation as one form of data analysis. The reflection section in this paper shows that the approach posed potential risks around the emotional vulnerability of participants, with participants experiencing the project as cathartic and therapeutic. Some participants struggled with the process of thinking through objects as difficult. Although using a less conventional approach to research led to deeper, richer reflections and thus relevant, interesting data, concerns were raised around relevance, generalisability, and more generally the evaluation of the research. The paper concludes with a reconsideration of the identity boxes as a method.

Keywords: metaphorical representation; experiences; identity boxes; elicitation; creative methods; creative research; arts-based research; arts-based analysis;

Introduction

Over the last decades research approaches have seen many changes. Research has become more egalitarian and participants nowadays often are partners within the research process (Anyon et al., 2018; Domecq et al., 2014). Researchers have the ethical and moral responsibility to approach data collection in a less authoritarian, more participatory and accessible way. It is becoming more commonly acknowledged that the experiences of research participants may not necessarily be easily accessible through interviews or surveys on their own. It is against this backdrop that research has undergone a qualitative turn, a linguistic or narrative turn (Atkinson, 1997) and a reflexive turn (Foley, 2002). These changes are reflected in the research methods. Research relating to health and illness, in particular in relation to patients making sense

of and giving meaning to their experiences is well-established (Kleinman, 1988) through increased applications of narrative interviewing and storytelling and the exploration of life-histories (Charmaz, 1983; Williams, 1984; Frank, 2013). Calls for more embodied approaches to sociology and social research are now reflected in the turn towards the creative and participatory (Kara, 2015). More newly applied methods include arts-based methods (Bagnoli, 2009), artistic workshops (Tarr et al., 2018a; Tarr et al., 2018b), visual materials (Mason and Davies, 2009), photo-elicitation (Orr and Phoenix, 2015) and metaphors (Nind and Vinha, 2016) combined with interviews and narrative approaches. However, these methods are often not applied consciously and confidently, but have been used tentatively in the hope of fruitful outcomes in the form of different, more interesting, richer data (see Guell and Ogilvie, 2015; Nind and Vinha, 2016).

By contrast, I took a very conscious decision in employing a creative, participatory approach in my research work. In this article, I draw on my research into the construction of identity under the influence of fibromyalgia to explore a more material, embodied approach to research to elicit experiences and understand how participants make sense of these experiences. I present my particular approach to generating and analysing data in relation to participants' experiences through the implementation of an identity box project (Brown, 2017; Brown, 2018a; Brown, 2018b). I provide an overview of the research context and the approach taken to the research in order to provide the necessary background for the specific approach through identity boxes. I then describe the practical application of the identity boxes within the context of the research process and within the context of analysis. The subsequent reflection section discusses benefits and concerns regarding using identity boxes as a

method to elicit and analyse participants' experiences, which leads into the concluding thoughts around the identity boxes as a method.

Research context and approach

My research explores the construction of identity under the influence of fibromyalgia. Fibromyalgia is a complex, chronic condition that is characterised by persistent, widespread pain, fatigue, cognitive dysfunctions, sleep disturbances and psychological disorders (White and Harth, 2001). Typically, fibromyalgia symptoms wax and wane in form and severity within days, sometimes within hours. The cause for fibromyalgia is currently still unknown, and consequently the condition can only be diagnosed by excluding related illnesses and diseases. This lack of a definite process for diagnosis and the variability of the condition make it a doubtful and contested condition, even within the medical professions (Ehrlich, 2003; Wolfe, 2009; Mengshoel et al., 2018; Häuser and Fitzcharles, 2018).

Existing research into the lived experience of fibromyalgia considers the relationship between fibromyalgia and quality of life (Pagano et al., 2004; Arnold et al., 2008; Wuytack and Miller, 2011; Fletcher et al., 2015), status of health, employment and disability (Henriksson and Liedberg, 2000; Henriksson et al., 2005; Verbunt et al., 2008), emotional experiences of those diagnosed with fibromyalgia (Kashikar-Zuck et al., 2002; Cunningham and Jillings, 2006), experiences of relationships (Arnold et al., 2008; Wuytack and Miller, 2011; Armentor, 2017) and the impact of exercise (Sanz-Baños et al., 2016; Russell et al., 2018). Most of these and similar research projects, however, hone in on particular experiences of fibromyalgia symptoms, such as pain (Vincent et al., 2016), instead of trying to approach the illness experience holistically

with all its facets and including the sensory and bodily. Existing studies rely predominantly on interviews and surveys, although it has long been acknowledged within pain research that language and words are often inadequate in describing sensations (Scarry, 1985; Sontag, 2003; Eccleston, 2016), especially, if they include embodied and bodily experiences. Human understanding and experiences are not linguistic, but meta-linguistic, embodied (Finlay, 2015), which results in human communication being metaphorical (Lakoff and Johnson, 2003) to account for this embodiedness in our experience. The complexity of the fibromyalgia experience together with the imprecision of words meant that ethnographic research methods needed to be adapted.

My research also explores identity, which is defined on several levels, and refers to humans' culture (Calhoun, 1994) as well as to the collective understanding and sense of belonging to a group (Tajfel, 2010). We identify features, characteristics or traits, which we use as a basis for comparisons to determine how we "identify" and how we see ourselves. This concept of self (Stryker and Burke, 2000) tends to be coherent and more permanent, but we also move in and out of specific identities depending on external factors, such as socioeconomic, political or technological changes or contexts (Gee, 2000; Watson, 2008). Identity is fluid, and not simply formed, but actively constructed. So, to explore identity as a concept, we need to account for and include a constructive element within the data generation rather than merely trying to harness existing thought processes. Considering the vagueness and incorrectness of language, the embodied human understanding in relation to fibromyalgia, as well as the role of reflective practice in identity formation together with the fluidity of identity and the changeability of fibromyalgia, my research approach needed to allow for flexibility, variability and expressiveness, whilst maintaining the options for research participants

to expand and elaborate. This led to the development of identity boxes (Brown, 2017; Brown, 2018a; Brown, 2018b) as a method in order to achieve representations of the holistic, embodied, lived experiences of identity and fibromyalgia.

Identity boxes as a method

I developed my identity boxes project from three existing strands of work: memory boxes for dementia patients, memory boxes for cancer patients and Joseph Cornell's shadowboxes¹. Cornell's shadowboxes are artistic installations and sculptures that align everyday objects in order to represent deeper meanings (Waldman, 2002; Sommers and Drake, 2006). In the context of health care, memory boxes are used to support memory retrieval amongst dementia patients (Nolan et al., 2001; Hagens et al., 2003). Dementia patients and their families are encouraged to create a box of objects and items that can be kept in patients' rooms to help trigger memories. Through the engagement with the meaningful objects relating to past experiences and hobbies dementia patients' memories of those times are triggered. For dementia patients, whose capacity for short-time memory fails first, the present is experienced as confusing and distressing. Through engaging with relevant objects, patients' long-term memories are triggered and patients become centred and grounded in known experiences and memories, which they find more comforting and less confusing.

Memory boxes are also used with terminal cancer patients (Macmillan, n.d.). Patients create boxes of objects and photographs for their family members to prepare the patients and their families for the impending reality of death. This process is also

¹ Joseph Cornell's artistic Influence was the first and most prominent influence for me to create the boxes. There are, however, many other artists who explore identity (eg. Lucas Samaras, Tracey Emin).

about helping families to deal with grief and sense of loss. The families can use the objects and photographs to remember the patient that has passed away. For the patients, the creation of the memory box is a way of deciding how they want to be remembered and what they want to be remembered by.

In all these cases, the objects and boxes really are specifically created, meaningful assemblages to represent experiences and emotions, or to stand for some specific qualities and characteristics. The identity box project also uses objects, but instead of seeking to trigger memories, objects are used to represent answers to questions. Research participants were provided with a question, and in response to that question they were asked to find an object to represent their answer. There were five questions: "Who are you?", "What affects you?", "How do others see you?", "What role does fibromyalgia play?" and "What is life with fibromyalgia like?". Once the participants had chosen their object or objects to put into their box, they took a photo of the box at that stage, which they emailed to me together with a brief explanation of which objects were in the photo and what these objects represented. The photograph and the explanatory email were necessary to ensure that potentially weak photographs would not hamper the success of the project. The email with the photograph was also required to make sense of the participants' views, as items used in the boxes were very personal and individual. The aim of the identity box project was to provide participants with means to focus their thoughts, deepen their reflections and express their experiences more easily. Once all questions were answered and the box was truly completed, participants were asked to attend an interview as per Brinkmann and Kvale's (2015) concept of an interaction between participants and the researcher. During the course of these conversations, participants elaborated on their initial thought processes

and provided a deeper, less tentative interpretation and analysis of their own data, the objects and photos.

The identity box project as a method is based on, linked to and embedded in my conceptualisation of research: a process of meaning-making and the development of new kinds of thinking. Data is not collected, but created or generated, thus actively constructed. The completed identity boxes are therefore not a representation of truth, but a constructed representation of a personal and individual experience. The objects in the boxes combined with the interviews are "resources, mediators that [...] give shape to ideas" (Radley, 2010, 268). Travelling through the research journey (Brinkmann and Kvale, 2015) together researchers and participants are partners in exploring a phenomenon. Research was therefore the researcher making sense of the participant making sense of a phenomenon (Smith et al., 2009). The power differential between researcher and participant cannot be entirely obliterated, as the researcher still pursues a specific agenda. So, how data is generated and how participants get involved in the meaning-making process requires sensitivity: participants need to be actively involved and engaged; researchers need to be able to let the generated data come from the participants as far as possible without superimposing their views and interpretations.

Identity boxes as a stepping stone to analysis

Once all questions had been answered with the help of objects, I arranged for a video-conference call with the participants to elaborate on the tentative, initial interpretations. The video-conference calls were vital, as many participants were too fragile and ill to travel longer distances or receive visitors. Indeed, many planned meetings had to be rescheduled due to sudden onset of new or more severe symptoms or the aggravation of

the symptoms. As methodological and ethical considerations in relation to this study have been reported elsewhere (Brown, 2018a), I would like to focus on the meaning- and sense-making processes through the use of the identity boxes.

With the date for a video-conference scheduled, I undertook a first preliminary analysis of the data. That initial analysis combined elements of interpretative phenomenological analysis (Smith et al., 2009) with analytical approaches borrowed from visual methodologies (Prosser, 1998; Rose, 2016). Photographs and emails were initially reviewed in isolation of one another. First, the visual materials were coded with descriptive, organisational and conceptual observations. Subsequently, the textual data from emails were also coded before I combined the data to provide a third level of analysis, where the textual and visual data were considered jointly. The process was an iterative spiral process (Brown, 2018b) that allowed me to deepen my understanding of data task by task, on a single and multi-layered level. I then developed an interview schedule for the video-conference conversation. The basic framework for questions related around the organisation of the objects within box from one task to the next, and around probing more deeply for meanings hidden in and behind the objects and their physicality. These conversations were recorded, transcribed and subjected to analysis using NVivo. My analysis of the data stemming from the identity box project is that double hermeneutic meta-analysis of the researcher making sense of the participant making sense of an experience (Smith et al., 2009), which allows for valid, robust interpretations and explorations of phenomena. However, in addition to exploring and describing a phenomenon, potentially finding solutions to problems and thus providing new knowledge, social science research should have a deeper purpose (Denzin, 2016). Leavy (2015) argues that the researchers' aim should be

to engage holistically; to be evocative and provocative; to raise awareness and empathy; [...] and to open up avenues for public scholarship, usefulness and social justice (Leavy, 2015, pp.21-27).

To achieve this aim, researchers need to become more actively involved in generating ideas from raw data (Morgan, 2018). Rather than assuming that themes will emerge from coding, researchers need to consciously manipulate, assemble and reassemble (Deleuze and Guattari, 2016). The researcher is a bricoleur, “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, p.36). As researchers we should therefore let data speak and grab our attention, and then follow our "gut feelings" in tending to those "hotspots" (MacLure, 2011).

With this in mind, I applied a second layer of analysis to the identity boxes. Here is an example of how the identity box project was developed further into the creation of an artistic installation representing life with fibromyalgia. Figures 1 to 3 are examples from all the identity box projects to demonstrate one key element for the installation "Peace Treaty" (Figure 4). In answer to the questions "What role does fibromyalgia play?" and "What does life with fibromyalgia feel like?", participants tended to focus on strategies and mechanisms they use to deal and cope with the symptoms on a daily basis. The back rest in Figure 3 shows how Kate² makes sure she is as comfortable as possible at work, despite the persistent pain she experiences in her back. Other examples for practical mechanisms included the use of ice packs or heating pads, blankets and socks. However, the experience of life with fibromyalgia was also evident in and seeped through the participants' responses to other questions. In response to

² All names in this article are pseudonyms.

"Who are you?", Cathy added the gardening glove to her box (Figure 2); tellingly, there is only one glove, and that was Cathy's deliberate choice to demonstrate the limitations



Figure 1: Lisa's identity box



Figure 2: Cathy's identity box



Figure 3: Kate's identity

she experiences. She would like to be able to be a better gardener, especially because the gardening distracts her from pain and psychological disorder, which she experiences as distressing symptoms of fibromyalgia. Lisa's paint brush (Figure 1) shows that Lisa sees herself as an artistic and creative person, but feels that her creativity is hampered in the everyday experience and routine of living with fibromyalgia.

During the iterative, spiral analysis process and in follow-up questions in conversations, I deliberately searched for evidence of participants talking about life with fibromyalgia. I actively pursued to deepen my understanding of what fibromyalgia feels like to my participants. From that data, I gradually developed the installation "Peace Treaty", an armchair with TV, sidetable and meaningful objects that were purposefully chosen to represent the reality of a fibromyalgia flare-up. The aims of the installation were to provide an analytical output for the individual identity boxes as well as to

engage with the public and raise awareness around fibromyalgia. "Peace Treaty" (Figure 4) was shown in an art gallery in the Southeast of England as part of a three-week exhibition "Art is something much more dangerous" (O'Sullivan, 2001, p.128) on themes around domesticity, relationships and belonging. Through artistic means, the installation sought to inform, teach, raise awareness, and to develop empathy and understanding. "Peace Treaty" represented the lived experience and feelings of a chronically ill and disabled person; a person, whose physical condition confines him/her to the living room (Figure 4).³

³ Via a feedback book visitors were encouraged to engage in a meaning-making process to allow for a triple hermeneutic. Ethical considerations and lack of direct consent mean I cannot use these comments.



Figure 4: Peace Treaty

The relationship between the identity boxes and the final installation becomes evident, when we consider, for example, one of the objects in "Peace Treaty": a ball of wool with knitting needles. The wool and needles represent the participants' strategies used to distract from persistent pain. However, there is no finished knitting, which stands for the limitations of the repetitive movement of knitting, that would cause

additional pain. Of course, in reality, those diagnosed with fibromyalgia are producing knitware, but through intentionally highlighting failure and limitation, I aimed to communicate my participants' difficulties. The wool with knitting needles in Figure 4 is an active and assembled representation of the paint brush in Figure 1 and the gardening glove in Figure 2. In its final design, the installation used a wide range of objects, which were all described and explained on a hand-out available to gallery visitors (Figure 5). On the reverse page of the hand-out visitors could read the poem that lent the title to the installation (Figure 6).

Armchair, TV and telephone:

Many of those with fibromyalgia experience flare-ups of their symptoms, which mean they become house- or even bed-bound. In those times their lives revolve around the TV set, and the telephone to remain linked to their social network and the outside world.

Blanket, hot water bottle, ice pack:

Depending on the kind of pain, people with fibromyalgia use warmth and cold to try and manage their pain levels, in addition to the medication they are prescribed.

Medication:

Tablets prescribed for fibromyalgia include pain killers, anti-depressants, anti-convulsants, anti-inflammatories. In addition, it is highly recommended to take vitamins, especially vitamin B complex tablets to support the body's self-healing properties and promote general wellbeing.

Tea and tea lights:

Many people with fibromyalgia talk about trying to relax their bodies and minds, which they do by drinking teas, lighting candles and using aromatherapy scents. It appears that those with fibromyalgia respond particularly well to fruity, lemony and flowery scents.

Book, wool and knitting needles:

Fibromyalgia can be very disabling and patients often give up their jobs. In order to keep active and maintain a purpose in their lives, they try to engage in creative activities, like knitting and reading. However, pain levels often mean that they cannot actually do the activities, and brain fog results in processing issues so that reading is also a difficult, often impossible task.

Figure 5: Description of objects in Peace

Peace treaty

Who are you to call me invisible?
Just because I'm not like others.
I am like them in many ways.
I make sure you take notice of me.

Others may not always see me,
But I am there. I know I am.
And you know it, too.

I'm there when you forget what you wanted to say.
I'm there when you stop in your tracks.
I'm there when you slip away from life
Into the fog of oblivion.
I'm there when you tell your friends you won't make it,
Again.
I make you wince of pain.
I don't let you sleep.

How dare you ignore me.
When I am such a big part of your life,
The biggest part of your life.

If you don't want me to take all of your life
You need to change.
You need to learn,
Learn to accept me and love me for what I am:
A part of you.

So, let's stop our fight,
And try to get on.

Stop ignoring me, stop treating me as invisible,
And I won't need to make my presence known so much.

Listen to me,
And I'll let you get on with the other parts of your life.

But as soon as you forget me,
As soon as you call me invisible again,
I will return with a vengeance.

Figure 6: Poem "Peace Treaty"

Reflections on the use of identity boxes as a method

In the following section I provide reflections on the use of identity boxes for data collection and analysis. I draw on my experiences as a researcher, but I also use excerpts of conversations and emails from participants to substantiate my discussion.

For my research I recruited 44 participants who had received a formal fibromyalgia diagnosis at least three years before the research began. Recruitment was via social media and fibromyalgia support groups as well as through flyers and advertising at academic conferences. The 41 female and 3 male participants were aged between 28 and 68, with a mean age of 39. 35 participants took part in the identity box project, of which 15 completed all five tasks as designed with the material objects in a physical box. 14 participants switched to provide the data in an alternative, virtual format with the objects being chosen and described instead of creating a box. Six participants did not complete the tasks because their personal, health circumstances had changed to such an extent that they withdrew from the research without even having commenced an identity box. Depending on the participants' personal circumstances and how long participants took for each task, the projects took between 5 and 15 weeks.

The individualised approach of opening up to participants' ways of thinking and working impacted and enriched the data, as participants provided series of photographs, song lists, poems, extracts of diaries as well as personal musings and reflections. The identity box project therefore required more commitment on the part of the participants than a single interview or survey. This commitment was one of time and effort for the reflective process and the physical collection of the objects, and of emotional commitment and engagement. On a practical level, participants had to get a box organised, had to then find objects in response to questions, move those objects into the

box, take photos and email those through before repeating the process. In many instances, the objects that needed to go into the box were of such personal meaning that participants either regularly used them and so needed to consistently them in and out of the box for the duration of the project; or participants did not feel comfortable putting their prized and valued objects into a box with other less important items. It was almost as if putting the important, personal object into a box with others, less relevant ones devalued them.

I have tons of other giraffes throughout my home and I've got a lot of giraffe print strewn about. The truth is there wasn't much I could bear to place in a box. Everything is sort of feng shui'd in a way the soothes me. Prob a little crazy to say I would have a hard time parting with. (Lily, interview).

The emotional, physical and practical commitment was particularly poignant with one participant, who had very recently had relatives move into her house. Many items were still in boxes and in storage, and so, whilst she was keen to complete the project and to engage with material and metaphorical representations, she could not really bring herself to deal with boxes and physical objects.

The, the questions won't bother me, it's about actually the stuff, because and I'm having a lot of trouble with stuff in my house at the moment. My mother, my grandmother moved in with me. [...] So now we live in a multi-generational household and she just brought too much stuff, and so my house is overflowing, for someone who likes, you know, tidy desk, tidy mind, it's quite stressful already. So just have to find things and use them, and to talk about things again, I think it would have been the limit. (Sue, interview).

This leads into another relevant aspect: the role of emotions within the identity boxes. From a researcher's point of view, it is important to get to the meaningful,

personal level of participants' thoughts and ideas, but potentially neither the participant nor the researcher are prepared for unleashing unrecognised emotions. This is particularly important to consider when working with participants who may not be used to reflective practice in the context of their everyday life. As a researcher I have not received formal coaching or counselling training, but I can build on my experience as a teacher to support participants with their emotions in interviews. In this project using the objects for the identity box, the participants were on their own during the process of reflecting and selecting objects. They did not have the immediate, personal contact to provide the safety of dealing with the emotional impact of the activity. The emotional impact of the reflective process is best exemplified with participant Sally, who dismantled her identity box as soon as the project was finished:

I actually dismantled it the minute that I sent you the final photograph (laughs); I didn't want to look at it. [I felt] relieved, relieved that it was over [...] it's just one of those things that was a lot harder than it should have been, and I was so grateful to have finished it. (Sally, interview)

Many participants, and indeed Sally, experienced the identity box as therapeutic and cathartic. Although Sally dismantled the box as quickly and as soon as she could, she was one of the participants who described the experience of creating the box as most transformative.

Before we started this project I was completely fine with the idea of having fibro, I thought I was accepting of myself as a person. [...] but now looking at the objects, thinking about what I put in the box, I'm probably more fake because I'm always fighting, but then if I were to put things I the box that reflected the true me, I wouldn't know where the start. Yeah, I just need to cut myself some slack and find out who I am. (Sally, interview).

To Sue, the process demonstrated that there was more to her, and that she needed to find out more about herself, especially in relation to the illness experience. She talked about not being true to herself before the project because she had thought she was a down-to-earth person accepting the position she was in, when through the project she realised that she was fighting against the illness after all. The process foregrounded that despite the condition there was still a person that had always been there and that still had a lot to offer and give back.

Some participants enjoyed the project because it tied in with the advice given to them about managing fibromyalgia: keeping a diary. However, in practice, diary-keeping or journaling through writing regular entries is not sustainable for many:

I don't really have a diary or any sort of mental record. Maybe I should have done. [...] I'd write like one page and then I'd go, well this is so much I don't need, and I had about three or four notebooks with beginning starts, and unless I wrote them and burned them, unless I did it as like a, you know, cathartic exercise, and burned them I wouldn't do any reflections (Sue, interview).

The participants saw the potential of the identity box as a more accessible alternative to maintaining a diary or journal. To them, the project almost represented a time capsule of their experiences at this specific point in their lives, and they could see potential in re-running the project at different times in their lives to see and track personal development and changes:

[Repeating the project in a few years] would be great experiment, no, just, just to be even waiting just six months and try it again to see how much you've changed. (Lisa, interview).

Another important aspect was the engagement in reflective practice itself. Where reflections and reflective practice are concerned, written entries are often descriptive and not as analytical as they could be (Fook et al., 2006) and diary keeping and journaling tend to be focussed on and limited to specific areas of life, such as specific events or happenings on the day (Thompson and Pascal, 2012). However, as part of the identity box, participants' views become broadened, widened and deepened. This is because they are trying to go into themselves, see themselves and think of how others see them. The view becomes a lot more holistic and the reflections deeper, often to the extent where the reflections became meta-reflections:

I'll look over this [the questions for the identity box task] again and get back to you soon. I always keep a diary so I'll utilise it. (Cathy, email).

Through the identity box participants considered the entirety of their experiences and reduced that entirety to its absolute essence in order to be able to find a representation of that experience in response to a question. In effect, participants applied phenomenology by going “to the things themselves” (Husserl, 1901/2001). As a consequence, participants became more consciously aware of and in tune with their emotions and feelings. They were able to identify and work through them, which was experienced as unsettling, transformative and cathartic at the same time.

The fifteen participants who completed the identity box highlighted how the project gave them a sense of purpose. This sentiment of purpose was particularly prominent amongst those participants who were on long-term sick-leave or no longer working at all. Participants who undertook the virtual alternative equally confirmed their positive experience through the reflective practice. It could be argued that it was not necessarily the identity box as a method, but the research itself that provided that context for the sense of purpose. Being house- and bed-bound with limited social

relationships meant that participants felt they were burdens to their partners, families, friends and colleagues at work. Being part of the research was seen as a productive, though limited way of giving back to the wider community.

I feel proud [...] I feel like I'm fighting, like I'm potentially gonna help make someone's life better. (Clare, interview).

Participants may initially have had altruistic reasons to be part of the research, but through the process they were able to engage in social contacts: directly with me and indirectly through the installation in the art gallery. The participants' sense of purpose developed further with the reflective practice of the objects, as they started to realise that they were more than their illness, and that they were still important links in the social structures of their immediate and extended families. Lisa represented that position of hers with the glue (Figure 1, above), as she binds the family and holds family members together. Through participating in the identity box project Lisa and others acquired different tools for reflection. As such, it was the work with the objects and the identity box that allowed for that insight and shift in perception.

Whilst participants saw the benefits in the work with the metaphorical representation through the objects, there was a certain level of uncertainty about it. Participants often checked back whether they were doing the right thing and whether their work would meet my requirements and expectations.

Does it have to include regular dates? [...] Or include just specific, important events? (Cathy, email).

If I have misunderstood the assignment, please let me know. (Lisa, email).

Well, that's the end of Dorothy's "My box" for this week. I'm hope [sic] it answers the right question(s). (Dorothy, email).

This checking back about doing or saying the right thing did not feature in the interviews. It seems that participants were more insecure and unsure of their work, as the creative approach was largely new to them. Most participants had not dealt with memory boxes or Joseph Cornell's shadowboxes before the identity box project for this research. They had been vaguely aware of activities involving time capsules or memories, but had not seen these at work for research purposes. Some participants grappled with the research approach using objects and representations as part of the data generation.

Ok. I will try my best. My brain doesn't really work in an abstract way and reading all that [instructions for question 1], being completely honest, I do feel a bit concerned/stumped. (Jane, email).

How does this work? I mean the objects are my objects, no one else will have the same objects? (Abby, in conversation)

Abby's questions around the correctness of the objects also demonstrates her concern with generalisability, a concern that others shared. Traditionally, qualitative researchers have always had to justify validity, robustness, objectivity or generalisability of their research, especially in comparison to quantitative approaches. Over the last two decades qualitative research has become more accepted and as such there is no longer that same need for justifications in these ways. Frameworks and criteria to evaluate the quality in qualitative research in general and arts-based research in particular are more common-place. Common criteria are worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence (Tracy, 2010), incisiveness, concision, coherence, generativity, social significance and evocation and illumination (Barone and Eisner, 2012) and methodology, usefulness, significance or substantive contribution, public scholarship,

audience response, aesthetics or artfulness, personal fingerprint or creativity, and ethical practice (Leavy, 2015). Lafrenière and Cox (2013) provide a framework to assess arts-based works based on normative, substantive and performative criteria; the substantive and performative criteria refer to the technical and artistic skills and the effects on an audience, whereas normative criteria refer to methodological and ethical considerations of the research process.

These and similar frameworks still strongly link data analysis to approaches based on grounded theory with themes "emerging" through coding. The artistic analysis of the identity boxes is a different way towards developing findings, as this stage becomes an active construction, production and generation of themes (Morgan, 2018). Analysis as a process of conscious meaning-making and active manipulation of data requires the researcher to be transparent, reflexive and critical about the steps taken to arrive at textual as well as non-textual conclusions. Working on this cusp of art and research provides further grounds for considerations. If the analysis of the raw data, thus the artistic installation or outcome based on the identity boxes is art, then we need to ask ourselves the question of whose "piece" it is. I, as the researcher have created the installation "Peace Treaty" on the basis of and with the input of the participants who have supplied the object(s). The installation therefore "belongs to" and is "owned by" the researcher and the participants. What the installation did allow is the anonymisation of the raw data. Some of the objects in the boxes were very personal, such as marriage certificates, staff badges or passports. If photos of the boxes were shared, participants would be recognisable through their objects alone. In this sense, the installation based on the identity boxes provided a way of ensuring that the objects were made accessible and disseminated without exposing individuals, much like interview data is anonymised and pseudonymised.

Using the identity box project as a method for data collection and analysis has brought about attitudinal shifts amongst participants, transformations in perceptions in participants and gallery visitors and methodological developments for research. Naturally, the verbalisation of experiences and explanations of created data still played an important role, but expression through metaphors representations provided a first stage for data generation. By trying to ensure that all participants would find the data generation process accessible, and therefore being offered a wide range of creative approaches and formats for the tasks set, the forms of data submitted became more unwieldy and messier than data collected using conventional research approaches. Where then does this lead to? In the following, final paragraphs I would like to reconsider the method presented here.

Concluding thoughts

My research aim was to explore how those diagnosed with fibromyalgia construct and make sense of their public and private identity under special consideration of fibromyalgia as a holistic experience. This is because existing fibromyalgia research tends to isolate individual symptoms and focus on fibromyalgia as a special form of chronic pain conditions. At the same time and linked to this first objective, the study aimed to develop creative methods that would allow to capture holistic, embodied experiences that are considered difficult to express in words alone. For embodied experiences to be conveyed, a more embodied approach to research was required. Additionally, for research participants to be able to communicate their thoughts more accurately, they needed to be provided with means and tools to increase their levels of reflexivity. Using objects to represent answers and to create an identity box allowed for

deep engagement and consequently wider, broader views than interviews on their own.

The principles of including the material, the visual or the sensory as part of elicitation of experiences are not new; neither, are the inclusion of arts-based methods or the basic concept of the identity box. Where the method presented in this paper differs from previous work is in its conscious application from data generation through to analysis and dissemination. Through reflexively and critically considering and immersing ourselves in the textual and non-textual data, the participants and I consciously extrapolated key themes and developed these into the relevant output of the installation. Throughout all stages, we openly and fully transparently engaged with the meaning-making process of analysis. The identity boxes therefore became a tool to encourage deep reflections, and acted as a leveller for the power differential between researcher and participants. In this sense, the boxes are incredibly valuable as they provide unique insights into participants' experiences and feelings and thus, were a productive starting point for analysis and public engagement.

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References

- Anyon, Y., Bender, K., Kennedy, H., & Dechants, J. (2018). A systematic review of youth participatory action research (YPAR) in the United States: Methodologies, youth outcomes, and future directions. *Health Education and Behavior*, 1090198118769357.
- Armentor, J. L. (2017). Living with a contested, stigmatized illness: Experiences of managing relationships among women with fibromyalgia. *Qualitative Health Research*, 27(4), 462–473.
- Arnold, L. M., Crofford, L. J., Mease, P. J., Burgess, S. M., Palmer, S. C., Abetz, L., & Martin, S. A. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counseling*, 73(1), 114-120.
- Atkinson, P. (1997). Narrative turn or blind alley?. *Qualitative Health Research*, 7(3), 325-344.
- Bagnoli, A. (2009). Beyond the standard interview: the use of graphic elicitation and arts-based methods. *Qualitative Research* 9(5), 547-570.
- Barone, T. & Eisner, E. W. (2012). *Arts Based Research*. Sage.
- Brinkmann, S., & Kvale, S. (2015). *InterViews: Learning the Craft of Qualitative Research Interviewing* (3rd ed.). Thousand Oaks CA: SAGE Publications, Inc.
- Brown, N. (2017). The construction of academic identity under the influence of fibromyalgia. In: Henderson, H., Pennant, A.L. & Hand, M. (eds.). *Papers from the Education Doctoral Research Conference Saturday 26 November 2016. School of Education*. Birmingham: University of Birmingham. pp.18-25.
- Brown, N. (2018a). Video-conference interviews: Ethical and methodological concerns in the context of health research. *SAGE Research Methods Cases*. Available at: <http://dx.doi.org/10.4135/9781526441812>
- Brown, N. (2018b). Exploring the lived experience of fibromyalgia using creative data collection. *Cogent Social Sciences*. Available at: [DOI: 10.1080/23311886.2018.1447759](https://doi.org/10.1080/23311886.2018.1447759)
- Calhoun, C. J. (1994). *Social Theory and the Politics of Identity*. Cambridge, MA: Blackwell.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5(2), 168-195.

- Cunningham, M. M., & Jillings, C. (2006). Individuals' descriptions of living with fibromyalgia. *Clinical Nursing Research*, 15(4), 258-273.
- Deleuze, G. & Guattari, F. (2016). *A Thousand Plateaus*. London: Bloomsbury.
- Denzin, N. K. (2016). *The Qualitative Manifesto: A Call to Arms*. Routledge.
- Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... & Erwin, P. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research*, 14(1), 89.
- Eccleston, C. (2016). *Embodied – the Psychology of Physical Sensation*. Oxford: Oxford University Press.
- Ehrlich, G. E. (2003). Fibromyalgia is not a diagnosis. *Arthritis and Rheumatism*, 48(1), 276.
- Finlay, L. (2015). Sensing and making sense: Embodying metaphor in relational-centered psychotherapy. *The Humanistic Psychologist*, 43(4), 338–353.
- Fletcher, C., Booth, G., & Ryan, S. J. (2015). A new diagnosis of fibromyalgia: A qualitative exploration into quality of life. *Physiotherapy*, 101, e390–e391.
- Foley, D. E. (2002). Critical ethnography: The reflexive turn. *International Journal of Qualitative Studies in Education*, 15(4), 469-490.
- Fook, J., White, S. & Gardner, F. (2006). Critical reflection: A review of contemporary literature and understandings. In: White, S., Fook, J. & Gardner, F. (eds.). *Critical Reflection in Health and Social Care*. Maidenhead: Open University Press/McGraw-Hill Education.
- Frank, A. W. (2013). *The Wounded Storyteller: Body, Illness, and Ethics* (2nd ed.). Chicago: University of Chicago Press.
- Gee, J. P. (2000). Chapter 3: Identity as an analytic lens for research in education. *Review of Research in Education*, 25(1), 99-125.
- Giddens, A. (1991). *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Stanford: Stanford University Press.
- Guell, C., & Ogilvie, D. (2015). Picturing commuting: photovoice and seeking well-being in everyday travel. *Qualitative Research*, 15(2), 201-218.
- Hagens, C., Beaman, A. and Bouchard Ryan, E. (2003). Reminiscing, poetry writing, and remembering boxes: person-centred communication with cognitively impaired older adults. *Activities, Adaptation and Aging*, 27(3/4), 97-112.

- Häuser, W., & Fitzcharles, M. A. (2018). Facts and myths pertaining to fibromyalgia. *Dialogues in clinical neuroscience*, 20(1), 53.
- Henriksson, C. M., Liedberg, G. M., & Gerdle, B. (2005). Women with fibromyalgia: work and rehabilitation. *Disability and Rehabilitation*, 27(12), 685-694.
- Henriksson, C., & Liedberg, G. (2000). Factors of importance for work disability in women with fibromyalgia. *Journal of Rheumatology*, 27(5), 1271-1276.
- Husserl, E. (1901/2001). *Logical Investigations Volume 2*. (Moran, D., Dummett, M., & Findlay, J.N., transl. and eds.) Routledge.
- Kara, H. (2015). *Creative Research Methods in the Social Sciences: A Practical Guide*. Bristol: Policy Press.
- Kashikar-Zuck, S., Vaught, M. H., Goldschneider, K. R., Graham, T. B., & Miller, J. C. (2002). Depression, coping, and functional disability in juvenile primary fibromyalgia syndrome. *The Journal of Pain*, 3(5), 412-419.
- Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing, and the Human Condition*. United States of America: Basic Books.
- Lafrenière, D., & Cox, S. M. (2013). 'If you can call it a poem': toward a framework for the assessment of arts-based works. *Qualitative Research*, 13(3), 318-336.
- Lakoff, G. & Johnson, M. (2003). *Metaphors We Live By*. (Reprinted). Chicago: The University of Chicago Press.
- Leavy, P. (2015). *Method Meets Art: Arts-Based Research Practice*. (2nd ed.). Guilford Publications.
- MacLure, M. (2011). Qualitative inquiry: Where are the ruins?. *Qualitative Inquiry*, 17(10), 997-1005.
- Macmillan (n.d.) "Making a memory box" <https://www.macmillan.org.uk/information-and-support/coping/advanced-cancer/relationships/making-a-memory-box.html> [last accessed 23rd December 2018]
- Mason, J., & Davies, K. (2009). Coming to our senses? A critical approach to sensory methodology. *Qualitative Research*, 9(5), 587-603.
- Mengshoel, A. M., Sim, J., Ahlsen, B., & Madden, S. (2018). Diagnostic experience of patients with fibromyalgia—A meta-ethnography. *Chronic Illness*, 14(3), 194-211.
- Morgan, D. L. (2018). Themes, Theories, and Models. *Qualitative Health Research*, 28(3), 339-345.

- Nind, M., & Vinha, H. (2016). Creative interactions with data: using visual and metaphorical devices in repeated focus groups. *Qualitative Research* 16(1), 9-26.
- Nolan, B.A.D., Mathews, R.M. and Harrison, M. (2001). Using external memory aids to increase room finding by older adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 16(4), 251-254.
- Orr, N., & Phoenix, C. (2015). Photographing physical activity: Using visual methods to "grasp at" the sensual experiences of the ageing body. *Qualitative Research*, 15(4): 454-472.
- O'Sullivan, S. (2001). The aesthetics of affect: Thinking art beyond representation. *Angelaki: Journal of Theoretical Humanities*, 6(3), 125-135.
- Pagano, T., Matsutani, L. A., Ferreira, E. A. G., Marques, A. P., & Pereira, C. A. D. B. (2004). Assessment of anxiety and quality of life in fibromyalgia patients. *São Paulo Medical Journal*, 122(6), 252-258.
- Prosser, J. (ed.). (1998). *Image-Based Research: A Sourcebook for Qualitative Researchers*. London: Falmer Press.
- Radley, A. (2010). What people do with pictures. *Visual Studies*, 25(3), 268-279.
- Rose, G. (2016). *Visual Methodologies: An Introduction to Researching with Visual Materials* (4th ed.). London: Sage.
- Russell, D., Gallardo, I. Á., Wilson, I., Hughes, C. M., Davison, G. W., Sañudo, B., & McVeigh, J. G. (2018). 'Exercise to me is a scary word': Perceptions of fatigue, sleep dysfunction, and exercise in people with fibromyalgia syndrome – a focus group study. *Rheumatology International*, 1–9.
- Sanz-Baños, Y., Pastor, M. Á., Velasco, L., López-Roig, S., Peñacoba, C., Lledo, A., & Rodríguez, C. (2016). To walk or not to walk: Insights from a qualitative description study with women suffering from fibromyalgia. *Rheumatology International*, 36(8), 1135–1143.
- Scarry, E. (1985). *The Body in Pain – the Making and Unmaking of the World*. Oxford: Oxford University Press.
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. (Reprinted 2012). London: Sage.
- Sommers, J. and Drake, A. (2006). *The Joseph Cornell Box: Found Objects, Magical Worlds*. Cider Mill Press
- Sontag, S. (2003). *Regarding the Pain of Others*. London: Penguin Books.

- Stryker, S., & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social Psychology Quarterly*, 63(4), 284-297.
- Tajfel, H. (2010). *Social Identity and Intergroup Relations*. Cambridge University Press.
- Tarr, J., Cornish, F., & Gonzalez-Polledo, E. (2018a). Beyond the binaries: reshaping pain communication through arts workshops. *Sociology of Health & Illness*, 40(3), 577-592.
- Tarr, J., Gonzalez-Polledo, E., & Cornish, F. (2018b). On liveness: using arts workshops as a research method. *Qualitative Research*, 18(1), 36-52.
- Thompson, N., & Pascal, J. (2012). Developing critically reflective practice. *Reflective Practice*, 13(2), 311-325.
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851.
- Verbunt, J. A., Pernot, D. H., & Smeets, R. J. (2008). Disability and quality of life in patients with fibromyalgia. *Health and Quality of Life Outcomes*, 6(1), 8.
- Vincent, A., Whipple, M. O., & Rhudy, L. M. (2016). Fibromyalgia flares: A qualitative analysis. *Pain Medicine*, 17(3), 463–468.
- Waldman, D. (2002). *Joseph Cornell: Master of Dreams*. Harry N Abrams Incorporated.
- Watson, T. J. (2008). Managing identity: Identity work, personal predicaments and structural circumstances. *Organization*, 15(1), 121-143.
- White, K., & Harth, M. (2001). Classification, epidemiology, and natural history of fibromyalgia. *Current Pain and Headache Reports*, 5, 320–329.
- Williams, G. (1984). The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness*, 6(2), 175-200.
- Wolfe, F. (2009). Fibromyalgia wars. *The Journal of Rheumatology*, 36, 671-678.
- Wuytack, F., & Miller, P. (2011). The lived experience of fibromyalgia in female patients, a phenomenological study. *Chiropractic and Manual Therapies*, 19(1), 22.