

Stop-motion storytelling: Exploring methods for animating the worlds of rare genetic disease

Qualitative Research
2022, Vol. 0(0) 1–22
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DOI: 10.1177/14687941221110168
journals.sagepub.com/home/qjr



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Abstract

Qualitative research is increasingly challenged to think creatively and critically about how accounts of lived experience might be collected, collated, curated, and disseminated. In this article, we consider how forms of participatory filmmaking and animation might assist in the development of methodologies appropriate to accessing, revealing and representing the social worlds of families affected by rare genetic conditions. We trace how participatory animation, specifically stop-motion animation (a filmmaking technique involving incrementally manipulating objects to produce the semblance of motion) offers opportunities for enlivening qualitative research. We discuss the creation of a series of workshops which took participants through the process of producing their own animated film. Stop-motion storytelling as a method enabled us to encounter, and subsequently foreground, different narratives and emotions, whilst creating-together and watching-together prompted novel conversations. We move to reflect on how participatory animation can be a provocative and productive practice in the toolkit of qualitative research.

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Keywords

Animation, stop-motion, claymation, participatory video, arts-based research methods, rare disease, creative methods

Introduction

Stop-motion is an animated filmmaking technique which involves incrementally manipulating and moving objects between individually photographed frames, such that when stitched together, the frame-by-frame effect produces the semblance of motion. It is perhaps an unusual topic to be deliberated in a journal dedicated to the discussion and development of qualitative methods, but as we will go on to explain, stop-motion storytelling as a method has enabled our research to engage and centre different kinds of narratives, emotions and affects.

Our research involves working creatively and collaboratively with families affected by rare genetic conditions to explore the broader experiences of patients and participants in genomic medicine and research. This has prompted us to think imaginatively and critically about just how ‘accounts’ of patient experience can be collected, collated, curated and disseminated. Methodological creativity and plurality is increasingly recognised as enabling more nuanced perspectives, different modalities of knowledge, engagement with affective, multisensory and more participatory approaches (DeLyser and Sui, 2014; Kara, 2015; Lupton and Watson, 2021). Qualitative research is increasingly challenged to evoke, not just explain (Andrews, 2018; Thorpe and Rinehart, 2010; Todres and Galvin, 2008) and experiment with finding new ways to use narratives collected in research (Barbosa Neves et al., 2021; Parr and Stevenson, 2014). These trends and provocations, along with support and encouragement from people with lived experience of rare genetic conditions who have directly informed and guided our research, have led us to engage with arts-based-research methods. Drawing on Parr (2007: 115), we have been moved to consider how forms of filmmaking and animation might assist as part of the development of sensitive and participative methodologies appropriate to accessing, revealing and representing the social worlds of families affected by rare genetic conditions (particularly, at a time when the mainstreaming of genomics is reshaping some of these dynamics). In doing so, we aim to contribute to discussions about the place and possibilities of creative, arts-based, methods in qualitative research.

In this paper, we trace how participatory animation offers opportunities for enlivening qualitative research. We discuss and explain how we facilitated a series of workshops taking participants through producing their own stop-motion animation film, the value creating-together brought about, and how watching these films as a group produced novel conversations. To illustrate and demonstrate the benefits participatory animation created for us, we briefly discuss four films produced by participants as a way of demonstrating the different kinds of narratives, emotions and affects stop-motion storytelling as a method enabled us to encounter and subsequently foreground. We conclude by reflecting practically and critically, from our perspectives as researchers as well as drawing on observations from participants, about how participatory animation may be a usefully

provocative and productive practice in the toolkit of qualitative research. In doing so, we offer contributions to understandings of animation-as-method, whilst highlighting the value and usefulness of participatory, creative and visual methodologies for studying the social worlds of health and disability. Firstly though, it is helpful to (briefly) explore how genomic medicine is creating a changing landscape of expectations for those affected by rare genetic conditions (Borup et al., 2006; Horst, 2007; Kerr et al., 2019).

Understanding life with rare disease alongside the promise of genomics

Scholars across a variety of disciplines have created an extensive literature illuminating the complex and emotional familial experiences of rare genetic disease from a diverse range of perspectives (Baumbusch et al., 2018; Boardman and Clark, 2022; Dimond et al., 2022; Featherstone et al., 2006; Liddiard, 2018; Navon, 2019; Pelentsov et al., 2016; von Der Lippe et al., 2017). Building on this literature, our research is interested in exploring how affective and promissory discourses surrounding genomics are (re)shaping the social worlds and lived experiences of those within this community who have been offered whole-genome-sequencing.

In 2012, the UK Government launched the 100,000 Genomes Project, an effort to apply whole-genome sequencing to the study of rare diseases, cancers and infections. The project has claimed to have ended long diagnostic journeys for many patients and their families – including a diagnostic yield in participants who had undergone previous genetic testing. Many diagnoses provided were reported to be immediately clinically actionable – though for others, the findings provided remain of unknown usefulness (The 100,000 Genomes Project Pilot Investigators, 2021). The project has been hailed as revealing the potential of a whole-genome-sequencing approach to the diagnosis of rare diseases, and in patients with specific presentations genome sequencing is now the first-line test in the NHS (The 100,000 Genomes Project Pilot Investigators, 2021).

The mainstreaming of genomic medicine (the shift from single gene to whole-genome-sequencing) is leading to new imperatives, obligations and responsibilities for both clinicians and families (Weller et al., 2022). Such a mainstreaming is enmeshed with anxieties, expectations and hopes about the promissory offerings of genomics, and set against the complexity, messiness and uncertainty of the science (Horst, 2007; Kerr et al., 2019, 2021; Mwale and Farsides, 2021). With genomics set to play an ever-increasing role within public healthcare, understanding how patients and their families see the impact of the celebratory and positive imagined futures (presented by scientists, clinicians and policy makers) on their (everyday) lives is of critical importance. The promissory claims associated with (and imagined by) genomic futures are fragile and contested, particularly when set against everyday experiences of health and healthcare (Kerr et al., 2021). The ‘everyday’ is important here, as we will go on to show shortly, few of the animations produced through our workshops focussed on ‘genomics’ itself, no-one animated a next-generation-sequencer, nor even strands of DNA, instead, animation offered us an insight into the wider social context that remains, and the everyday realities of families caught up amidst genomic excitement. Similarly to Liddiard (2018: 11), our aims are to enable our

participants to situate their stories against and amongst ‘the myriad stories already told about their lives by “experts”’.

Co-producing participatory animation

Participation and co-production are at the heart of our research. Discussing the ethos and importance of co-production, we locate participatory animation as a research method building on the multi-disciplinary methodological developments associated with the participatory turn (particularly, participatory video) before moving to highlight how animation can provide new ways in which we might evoke, understand and (re)present experiences of research participants. Reviewing literature around participatory animation, we trace themes relating to the creative affordances of animation, where materiality and embodiment actively shape possibilities for how knowledge might be produced, the social opportunities animating-together produce, and ideas relating to the mobility and impact of how such animated tales might travel.

Efforts to embed equity, partnership and meaningful partnership through forms of ‘co-production’ in research have been positioned as critical to developing ethical collaborative disability research (Liddiard et al., 2019). This involves challenging hierarchies between researcher and researched and validating multiple forms of knowledge and experience (DeLyser and Sui, 2014). Exploring ways to create space for different knowledges and voices in research (Henwood et al., 2019), has led many to turn towards creative and arts-based practices, including both photography (Prins, 2010) and videography (Kindon, 2003).

Using filmic practices to co-produce research has a rich legacy in qualitative inquiry (Milne, 2016). Lunch and Lunch (2006: 10) emphasise, ‘the idea behind this is that making a video is easy and accessible, and is a great way of bringing people together to explore issues, voice concerns or simply to be creative and tell stories’. Using video can open up new styles of expression, perception and understanding, providing different modalities of knowledge (re)presentation, production and dissemination (Blazek and Hraňová, 2012; Marzi, 2021; Parr, 2007).

We are interested in a sub-set of participatory video work: participatory animation. Animation is a process in which figures are manipulated to appear as moving images. Giving life and mobility to the inanimate in this way can be a powerful representative force that is affective and expressive (Blair, 2014; Boyd, 2017; Flynn and Chapman, 2011; Gammidge, 2016). Animation allows participants to tell stories in unique ways and can bring an innovative contribution to ethnographic representations (D’Onofrio, 2020). D’Onofrio (2020: 193), drawing on Pink (2001: 24), argues participatory animation provides a methodology allowing for ‘ways of using image and sound to create expressive, rather than realist, representations of aspects of human experience and discourse’. For D’Onofrio (2020: 193),

“The animated film can become the very method that can help us identify and represent particular kinds of experience and perceptions, which do not find adequate expression elsewhere.”

Participatory animation provides a way for participants to discuss their lived experiences, reflect on challenges they face, whilst producing tangible outputs that can travel, enabling stories to gain a wider visibility (Morelli, 2021). As a method, animation can ‘bring into view what cannot be captured by a camera—the oneiric, the absurd, the surreal’ (Morelli, 2021: 340), experiences that are crucial to understanding social life – particularly, allowing lived experiences that feel invisible and unheard to be represented (Morelli, 2021). The act of animating is an active process that allows people to redefine, renegotiate and resist claims and memories (D’Onofrio, 2020; Sjöberg and D’Onofrio, 2020). Animation provides freedom to tell a story, but also freedom ‘to choose *how* to tell it’ (Morelli, 2021: 341 emphasis original). Animation provides a means for conveying emotional and self-forming experiences, particularly, ones which are resistant or difficult to represent in words (Blair, 2014). It allows people to show their stories, rather than having to tell (Gammidge, 2016). Animation making can provide a safe space for exploration and experimentation (Budach et al., 2020). It can allow for ‘things not yet explored to emerge and for a process that feels like “becoming” rather than something already precisely known’ (Budach and Sharoyan, 2020: 470). That is animation can prompt new ways of seeing. D’Onofrio (2020), drawing on Skoller, argues participatory animation fits perfectly with social science agendas, as ‘these films are not just attractions, they are forms of knowledge’ (Skoller, 2011: 209).

Animation involves the body in specific ways, shaping how knowledge is produced and represented (Sjöberg and D’Onofrio, 2020). An embodied physicality is involved, in doing, creating and sensing; ‘while animating, the body of the animator is fully inhabiting the space and the time of the creative process’ (Sjöberg and D’Onofrio, 2020: 742). Thus, what is produced is an embodied narrative (Gammidge, 2021), with stories emerging through doing and making. The materiality of the medium is also important. Ali et al. (2014: 60) utilised clay animation to explore the emotional needs of stroke patients, and describe how for their participants, ‘when the clay started falling apart, there would be responses of humour and recognition of their own vulnerability’. The mediums through which stories are told are important in effecting what stories are told, highlighting the generative potential of arts-based methods to create space for different stories to emerge. As Haraway (2016: 12) describes, ‘it matters what matters we use to think other matters with; it matters what stories we tell to tell other stories with’.

Animation is a methodological approach that actively engages participants in the production and (self)representation of knowledge (Morelli, 2021), with the process of creating animations providing a conduit and catalyst for participants to reflect on their experiences (McAra, 2021). As with many arts-based research methods, the practice of creation is as important as any final product. The activity provides a shared and highly social environment where participants can talk freely and create a feeling of community (Ali et al., 2014).

Sharing animations can be a route to producing empathetic responses (Budach and Sharoyan, 2020). The films made can, with participants permissions, have a life long after the initial research, encountering multiple audiences where they will have different affects and evocative forces (Parr and Stevenson, 2014). That is these films have the potential of acting as ‘affectual interventions’ – stories which do more than just ‘represent’ but can

also generate and mobilise actual change (Cameron, 2012; Parr and Stevenson, 2014: 566) (for an example of the legacies and afterlives of creative social research, see Parr (2021)). Particularly, we see the value of these stop-motion stories ‘to act as resources and as mediums of knowledge transfer and exchange’ (Parr and Stevenson, 2014: 567), through emphasizing knowledge located within participants’ narratives and experiences. As Featherstone et al. (2006: xii) argue ‘a sound appreciation of everyday social reality is of profound importance for professional practice’ – thus, finding ‘ways to make living systems actually come alive’ (Deacon, 2000: 97) through qualitative research is of ever-increasing significance. Here, we would argue animated narratives have capacity ‘to produce ethical relations between otherwise distant and unequally positioned subjects’ (Cameron, 2012: 583) – as we will go on to demonstrate.

Developing a method for stop-motion storytelling

Returning to the ethos of co-production, our research is directly informed and guided by people with lived experience of rare genetic conditions. This group has integrally shaped our research in all its extents, including research questions, methodology, recruitment and dissemination. Conversations with this group indicated an interest in, and encouragement to, explore ways of researching using arts-based methods. When we suggested the unusual method of stop-motion animation, the idea attracted curiosity, excitement and engagement – though paired with tentative anxieties.

Working with an artist-facilitator we designed a series of workshops to take participants through the process of producing their own stop-motion animation film, step-by-step. Our artist colleague had extensive experience of utilising animation in clinical settings and with people who have suffered trauma. This project was granted ethical and research governance approval by the Brighton and Sussex Medical School Research Governance and Ethics Committee (ER/BSMS9KQM/4).

Given our focus on understanding lived experiences of those who have been offered whole-genome-sequencing, we worked with regional rare disease networks, support groups for ‘syndromes without a name’, and networks associated with patient involvement relating to genomics to recruit participants who had relevant experience. Recruitment was part of a broader project (c.f. Gorman and Farsides, 2022), and the time-commitment involved in attending the workshop series proved to be a particular barrier for participants who had attended previous workshops. However, we recruited six participants who committed to attending the workshops – to our delight, this included participants who had previously opted out of related research based around more textual creative practices, highlighting the appeal of visual research methods and their ability to draw in different voices.

Ultimately, for this work, the participant group was all female, and ranged from mid 30s to late 40s. All were mothers of children affected by rare genetic conditions, with many having a significant level of caring responsibility as a result. Likewise, all had experienced the process of whole-genome-sequencing from (their children) participating in large genomic medicine projects, such as the 100,000 Genomes Project and/or the Deciphering Developmental Disorders Study. Some had received a diagnosis as a result,

ending a long ‘diagnostic odyssey’, others were still waiting, with their children remaining undiagnosed. Participants’ children were affected by a range of different, but frequently complex physical and cognitive impacts. Rather than a shared condition or diagnosis, it was the shared experience of whole-genome-sequencing that brought our participants together. Their experiences of life with rare genetic conditions had been profoundly shaped by the novel diagnostic prospects promised by genomic medicine and the enrolment of their families within.

We had not intended to solely recruit parents, nor solely recruit an all-female group. We went to great lengths to try and recruit men, but did not succeed in garnering interest (at least, for the animation work, other research has had input from men/fathers). Why this happened, we cannot quite say. Perhaps there are intersections between the gendered labour of ‘care’ being revealed here, [Baumbusch et al.’s \(2018\)](#) work exploring the experiences of parents of children with rare diseases similarly commented on the gender imbalance in participant response to their work. However, [Kornhaber \(2016\)](#) notes that the social worlds of the animation studio have traditionally been deeply gendered with women’s contributions silenced, so it is positive that re-appropriating animation-as-method has not acted to reify this dynamic. Though clearly, further investigation regarding the intersection between gender and rare disease advocacy, and gender and arts-based research methods, are required.

With this work taking place during the Covid-19 pandemic, and with many of our participants affected by vulnerabilities within their families, we made the decision to develop our workshops online. This required thinking creatively, and finding ways to adapt a hands-on practice into something that could be taught and facilitated remotely. We were conscious of accommodating the availability of people with often complex caring responsibilities. Ahead of the workshops, we sent participants an animation resource pack containing a variety of materials and equipment, including a smartphone-tripod, wire armatures (a framework around which a character-figure is constructed), a selection of clay, sculpting tools, pens, pencils and paper and card for creating backgrounds.

The first workshop introduced participants to the technology which would be used to create and produce their films, a free smartphone app ‘Stop Motion Studio’, and the basics of animation by practising animating small lumps of clay. This involved taking a photo, then slightly moving or moulding the lumps of clay, before taking another photo, and repeating in a gradual process. The app stitches the photos together, giving the impression of movement; animation. Participants were encouraged to see what happened, what narrative emerged and what creations came out of slowly documenting their manipulation of the clay, step-by-step. Once people became comfortable, they were tasked with incorporating an object into their experimental practice films, again incrementally moving objects to create a sense of life and see what narratives emerged. Finally, participants were taught how to add sound to their short clips, before sharing their creations with the group. This playful process allowed participants to get to grips with the principles, practices and potentials involved in stop-motion storytelling.

We aimed to carefully curate expectations: there was no ‘right’ or ‘wrong’ way to do animation. It was not about creating a lengthy feature film, but exploring the stories that could be made and told using animation, and whether that led to making or telling

different stories, or telling stories in a different way. Whilst we were keen to enable our participants to tell stories reflecting how the promissory discourses surrounding whole-genome-sequencing might reshape their expectations about life with rare genetic conditions, previous work using stop-motion animation by [Gammidge \(2016\)](#) found that giving participants freedom and agency in choosing what they make their films about can lead to greater engagement than if a theme is imposed externally. Offering people a choice is a powerful way of creating participation and parity, enabling safety, control and directorial authority in allowing people to navigate sensitive topics ([Gammidge, 2016](#)). For our participants, this was important, allowing them to tell their stories with freedom, rather than forcing them to mould their stories around predefined academic interests. Thus, in the latter part of the workshop, we introduced participants to the task stretching across the rest of the sessions: the project of telling a story. Whilst we did not want to impose a theme, we did introduce ‘narrative scaffolding’: that participants begin by creating a protagonist with a task to achieve or a problem to overcome – one participants might relate to. We encouraged participants to let their characters ‘tell’ them what the overarching story might become, with stories emerging through the practice of doing and making; an embodied narrative.

Subsequent workshops guided participants through the process of crafting their characters, supplying them with various techniques and tips – both editorial and sculptural. During these sessions, participants shared their developing films, receiving feedback and suggestions from the facilitator and wider group. People were keen to check if the emotions and emerging stories they’d intended and hoped to convey through their clay characters were being perceived. The process of animating creates a sense of community where participants can talk freely as they experiment and explore with different narrative forms ([Ali et al., 2014](#)). Thus, with participants’ permissions, we recorded the workshop sessions, as a way to capture and reflect on what animating produced discursively (and allow participants to remain involved if they were unable to attend).

We ran four workshop sessions that enabled participants to begin to feel comfortable and confident in working with animation as a storytelling modality. After these initial workshops, we set participants the task to work on their films for several weeks, with a view to having produced something they considered as complete by a set deadline. We assured participants that their films did not need to be lengthy, or polished, but rather we hoped animation might provide means of telling different stories differently. To facilitate this, and because participants enjoyed getting together to work on their films and talk about the impacts and realities of the narratives they were raising through their animations, we arranged a series of ‘drop-in’ sessions. These drop-ins provided space for valuable conversations. Others preferred to work on their films in their own time. Flexibility is an important consideration in enabling research to be accessible to people affected by disability ([Liddiard et al., 2019](#)).

Once participants had completed their films, we brought everyone together for film-screenings, and to discuss and explore participants’ intentions and experiences of producing their films (transcribing discussions that occurred). Our film screening events came to act not too dissimilarly to discursive focus groups, though it is important to note

these were not in the artistic tradition of providing critique nor about extracting analysis. Rather, we were interested in what the process allowed participants to foreground and what was brought to their attention by this – admittedly unusual – method of creating representations. As [McLaughlin and Coleman-Fountain \(2019\)](#) suggest, in doing visual research it is not enough to ask participants to create visual artefacts, what is also required is that researchers explore creators' intents. The films thus served as something of an elicitory device, allowing us to explore deeper themes and topics participants had already chosen to surface ([Bagnoli, 2009](#)). By embedding the films as part of these discussions the ensuing conversations were different than if we had run a conventional focus group with families affected by rare genetic conditions (and, different to the conversations that ensued from utilising other arts-based research methods [c.f. [Gorman and Farsides, 2022](#)]).

In what follows, we discuss and report on our experiences (and, those of our participants) of utilising a participatory animation approach. In doing so, we briefly discuss four of the films (some participants opted not to share their films beyond the group) produced through the process, in order to illustrate the methodological offerings and potentials stop-motion storytelling can bring. By exploring the filmmaker's descriptions, aims and goals, and the conversations the films provoked, we can begin to demonstrate how this method might contribute to widening representations of the social worlds of families affected by rare genetic conditions. Our aim is not to report on, or analyse, our findings (this will be written elsewhere), but to demonstrate and explain how this approach opened new conversations, created space for different voices and allowed us to centre different affects and emotions within our research. Through such, we hope to enliven our descriptions and reflections of the methodological opportunities on offer here.

A method for animating the worlds of rare genetic disease

There is a playfulness to our titling here. We of course refer to animating as the process of making an animated film and creating the appearance of movement. However, we also draw inspiration from the other meanings associated with 'animating'; to represent as alive, to impart liveliness, vividness, or interest to something, to enliven. These latter semantics are important here for our goals of finding methods capable of evoking the social worlds of people affected by rare genetic disease. Particularly, in a way that allows and enables people to tell stories that resist a singular frame of medicalisation and instead bring into focus different narratives; narratives that celebrate the joys, excitement, fervour, vivacity and overall sense of life and vitality that for our participants, characterised their worlds and relationships with their children.

Participants quickly embraced the potential stop-motion animation offered, though some struggled to decide on the stories they wanted to tell, and spent initial workshops trialling the creation of different characters that might suit different stories, hoping through the playful creation of these characters a narrative thread might emerge they were comfortable to share, but also might provide a valuable commentary. Early ideas for storylines and characters included a dinosaur, to represent the 'old fashioned views and language that people might use'; a character in a wheelchair, challenged by an obstacle in the built environment 'to demonstrate the social model of disability'; a clay puppet

representing the mother of a child with a rare genetic condition trying to go about her daily life whilst encountering the negative things friends and healthcare professionals say, and seeing the effects of how that makes her feel through the gradual deterioration and coming undone of the clay puppet, with the materiality of the clay prompting a particular story. As [McLaughlin and Coleman-Fountain \(2019\)](#) note, the utilisation of visual methods in disability research often acts to counter existing public images of disability (something which must be recognised in any analysis).

The stories participants told whilst animating often sparked conversations, recollections and stories of both similarity and solidarity amongst group members. Participants tell us that many of these conversations have continued. Animation provided a new mode of communication that led to people opening up and bringing different stories to the fore. The process of smoothing and sculpting and sometimes repairing their plasticine in turn smoothed the way for uncomfortable conversations. Participants regularly remarked how ‘doing something so hands on and physical has made us think’.

‘Don’t worry, he’s friendly’

[\[Supplemental Video 1\]](#)

The film begins with a brightly decorated set, rolling green hills and a blue sky filled with clouds in the background, whilst in the foreground a bench is placed in between green bushes, rocks and a tall building: a park. A character, a small girl, walks into view, we hear her footsteps. She turns to the camera and waves, ‘hello!’, before sitting down on the bench and letting out a deep breath of relaxation. She smiles. A small dog appears. The girl, noticing it, raises her arms and gasps in shock. The dog moves towards her, and she quickly stands up, making fearful noises, and runs away. The film switches to a close up of the dog, in quick, juxtaposing frames, the small dog is interpolated by a large angry beast of a dog, with a slavering expression. The dog barks, growls. Its expression intensifies further and we see the small girl backed against the wall, terrified. As the dog continues to bark, she breaks down in tears. Another character appears, the dog owner. ‘Don’t worry, he’s friendly’ they croon.

In the viewing sessions the filmmaker explained how the little girl represented her daughter, a child with an undiagnosed genetic condition, and ‘the reason there aren’t any words – beyond hello – is because [child] is nonverbal’. She went on to explain:

“She’s got a real dog phobia and is terrified and will just freeze. She will just go very quiet, and in herself, and freeze. And you know, everyone in the room doesn’t seem to understand, can’t seem to see that she’s under a lot of stress and anxiety, and is really not happy. No-one else seems to notice, everyone is actually oblivious. To someone that doesn’t know her, they won’t be able to tell ... it’s extremely stressful. I’ve tried to explain, but people just don’t quite get it. People just go, ‘Oh, don’t worry he’s friendly’, that is what everyone says.”

Whilst the film is ostensibly about a fear of dogs and the challenges of communication, it also raised many other themes in the ensuing discussions – in particular the challenge of negotiating everyday environments when your child is unable to articulate or display their

needs/fears in ways familiar to others. The idea of ‘Oh don’t worry’ that emerged from this film was noted as being strongly relatable for many of our participants. Conversations following the film involved participants reflecting on how such dismissive language frequently plays a role in medical settings, with ‘don’t worry’ being recognised as a phrase used by healthcare professionals to downplay concerns and brush off anxieties. That is things that may be seen as ‘everyday’ by healthcare professionals and therefore unworthy of attention in medical settings, can be significant for patients.

“That’s a thing the medical professionals do, they will be like ‘oh don’t worry’, or ‘it’s just...’ and I think just to brush something off quite lightly, because it’s not significant to you, is something that happens a lot, and it’s everyday for them so they don’t really think about it.”

“Yeah, the medical professional will be like oh don’t worry, that’s all it’s going to be, but it can be a big deal to someone else, especially if it’s something new.”

For us, it was exhilarating how the film and method surfaced such a detailed conversation about experiences of the challenges people faced. Several participants used the film as a pivot to discuss their (and their children’s) struggles to navigate communication conventions and neurodiversity, particularly when a disability might not immediately be visible to others (or even, formally diagnosed). Others discussed how this had led them to fear that medical professionals encountering a nonverbal child may not make the effort to understand their experience of distress and anxiety. Participants discussed how, despite being downplayed, these moments tended to be things that stayed with them, and came to shape how they approached future medical encounters, creating anxieties, reluctances, and above all, a sense of voicelessness. When set against the backdrop of novel whole-genome-sequencing technologies these minute interactions may easily be eclipsed, yet it is these moments of social interaction that come to characterise people’s experiences of medicine, and need to be foregrounded when we try to understand the lived experiences of those who have been offered whole-genome-sequencing. Stop-motion storytelling gave us a method through which to begin to understand this – and importantly – represent it back to healthcare professionals.

‘Professionals, remember, your words can last a lifetime’

[\[Supplemental Video 2\]](#)

We see a character in a wheelchair, initially smiling and singing to themselves as they move across the set. They encounter a clinician in green scrubs who kneels down and takes the wheelchair user’s foot in hand. ‘Let’s have a look at this foot’, the healthcare professional says. The main character recoils. Their shoe is quickly removed. A speech bubble appears, ‘this foot looks quite deformed’ says the healthcare professional. Tears appear in the eyes of the patient; their smile is turned upside down into a visage of sadness. Suddenly, surrealism kicks in, and a giant plasticine foot crashes down from the sky, crushing the offending doctor. The film cuts to words on a page, appearing letter by letter with added voiceover: ‘professionals, remember, your words can last a lifetime’.

When asked to introduce the context for this animated narrative, our participant explained,

“My daughter is non-verbal, but I find things are said in front of her that probably wouldn’t be said in front of another child who did have those communication abilities... We attended the appointment with the physio, and when we came out, she said ‘oh he was nice’, and I said, ‘well I wasn’t impressed with his language choice’, and she hadn’t even picked up on it, but it’s something that’s stuck with me ...He used the word deformed, and that’s what I came away with. I think there are things that our kids hear that they shouldn’t really have to. Professionals need to really rethink how they talk about kids in front of kids ... I don’t see why he chose to use the word deformed when there’s other words, you could rephrase it in so many different ways, but those are the words that he chose.”

In previous work, we have shown how accessing genomic medicine services can require engaging with complex scientific vocabulary in order to be confident in understanding, participating and obtaining, optimum care (Gorman and Farsides, 2022). This film prompted a discussion once again about language, the differences between technical languages and lay languages, and the impact such mismatches can have, with terms that might mean something straightforward or specific to healthcare professionals having the potential to be heard completely differently without a contextual-professional body of knowledge; the connotations, aspersions and questions that lead to words mattering and resonating even years later. Linked to this was the burden on parents when feeling they must, at times, adopt similar vocabularies to advocate for their child, feeling a tension between wanting to resist such language, and feeling required to replicate it when engaging in attempts to access support. This conversation about the use of words led to deeper reflections upon the medical gaze and claims that it rendered much of a child’s life invisible, whilst foregrounding negatives and limitations. For example as one participant described in conversations following watching the film:

“You want to be able to show the juxtaposition of the social model and the medical model, that we are saying our children are living happy fulfilled lives as part of our families, and that’s completely juxtaposed as soon as you get into a clinical situation, everyone starts talking clinical language and looking at what’s wrong and how you fix this person, and that juxtaposition, the medics need to see that other side”

Participants noted how the film signified possibilities for reclaiming a sense of power and agency through resistance to medicalised representations, and valued having had opportunities to ‘speak back’ via our research. There was a sense from participants that they often felt expected to play a certain part and follow a particular script, or tell a certain story, whereas playfully creating their own representations and narratives via our experimentations with stop-motion storytelling allowed them to reclaim a level of agency.

‘Ordering a Repeat Prescription’

[Supplemental Video 3]

The film opens with the words ‘ordering a repeat prescription’ appearing, before cutting to a character stood at a desk (or maybe a kitchen counter?) with a notebook and a phone. The character rifles through the notebook and picks up the phone. The text continues, ‘prescribed as a trial for a rare disease’. We hear the phone ringing as the woman patiently awaits an answer against an audible backdrop of telephonic blips playing busy signals and endless ringing. The text narrates that after several calls, the GP explains to the character ‘it can’t be prescribed by primary care’. The woman flicks through her notebook further, and returns to the phone, further dialling tones and busy tones echoing. This time, she gets through to the local hospital, who explain ‘it needs to be the specialist clinic’. The woman returns to the phone, increasingly hunched over the desk. The specialist who answers the phone proclaims, ‘yes’, and we see the character begin to stand taller, until the text continues, ‘but you’ll have to collect it here’. A disconnected tone plays loudly as they hang up, and the woman slumps to the desk, head in her notebook. ‘Arrgh!’ exclaims the text in angry capitals as various call-progress tones overlap in a blurring of noise. Finally, the narration explains, a new local consultant takes the call, who tells the woman ‘we’ve set up a joint clinic, we can now prescribe’. The woman is elated, a smile returns to her face and she raises her arms in celebration, the sound of clapping interspersing the phone noises, as she hangs up the telephone and collapses on her desk, exhausted.

The story is quite literal, and eminently relatable. Textual narration makes it easy to follow. The filmmaker described its origins as an attempt to capture ‘that feeling of “no, we can’t help you, we don’t know who can help you”’. She went on to explain:

“I was thinking of a time when I was trying to get a prescription organised for my daughter, and you phone up the GP to get it repeated and they say ‘oh no you can’t have it on primary care, we don’t find it on primary care, you’ll have to phone the consultant who prescribed it’, so they’re in London and you say ‘well can you transfer the prescription to the local hospital’, ‘no we can’t do that, you’ll have to come to London to collect the prescription’ which is ridiculous.”

The film captures the sense of exhaustion combined with dogged determination to get a job done – all of which become invisible once the task has been fulfilled. In doing so, the film draws attention to the invisible labour involved in living with rare genetic conditions, and how parents of children with rare genetic conditions are often implicitly expected to become ‘expert caregivers’ (Baumbusch et al., 2018) but also, in effect, medical secretaries for their children. A constant and exhausting effort to manage appointments, chase up correspondence, collate notes, understand medical terminologies, and interact between multiple different consultants, specialities and geographically dispersed healthcare teams. Yet despite the expertise they bring to the management of their child’s condition, in discussions following this film, participants reflected on how quickly and how often this expertise was undermined, with them regularly relegated to just ‘mum’

with that identity seen as all-consuming and rendered invalid in its ability to contribute valuable knowledge within a clinical setting. In this example, it was the combination of both the creation of the film, and the watching-together that unearthed and revealed shared narratives, and created solidarities amongst participants.

‘Birds’

[\[Supplemental Video 4\]](#)

We begin with a chorus of bird song. A woman sits calmly on a bench, a blue sky in the background. She looks relaxed and slowly raises her hand to focus her gaze into the distance. We hear the loud and distinctive caw of crows. The woman looks shocked, and gasps. The film cuts to a darkening sky, and the onset of a murder of crows, screeching and growing ever closer. The woman covers her face and tries to avert her eyes, holding her head in her hands as the crows circle around her. A crow lands on her head, sits on her shoulder, pestering her. She attempts to brush it off, but more crows are arriving. Suddenly, the sun appears, the sound of crows vanishes and more pleasant birdsong returns. The woman smiles, seeing something off camera, and opens her arms. A small boy wearing glasses appears and embraces the woman with an affectionate hug, and stillness and silence returns. In the background a small crow perches gently, but in the sky, the rest of the flock slowly fly away.

The filmmaker themselves described:

“The birds, it’s like I’m trying to enjoy something relaxing and then I’ve got these mental demons that just come out of the sky, so what would be a nice moment, suddenly I’m thinking about something I don’t really want to be occupying myself with. So the idea is, a nice day and then these horrible birds come along, and then the little figure comes in at the end as a reassurance. He was supposed to be the reassuring figure, and you see the joy in him, and you don’t worry about them anymore.”

When another participant noted that at the end one crow remained, the filmmaker reflected it represented that ‘it’s still going to be there, but you have to make peace with it, it’s always going to be there, even if you’ve pushed those thoughts away, they might come back again’. In a subtle and sensitive way, the film showcases the invisible stresses parents of children with rare genetic conditions have to cope with. Allowing people to construct a narrative on their own terms was important, as the filmmaker reflected:

“For me, I don’t like to put it down into words, it feels too difficult, or too permanent, whereas doing something that could be interpreted is much easier, and also I just find it relaxing doing stuff like this.”

There is a sense of reclaiming a narrative and agency here, with the filmmaker choosing to represent their child as the hero of the film; the source of reassurance, rather than the cause for concern. This sense of being an active social agent is an important narrative choice, given what we heard in group discussions about how frequently,

nonverbal children are rendered as passive in clinical settings and made vulnerable in social contexts such as the park. If we return to our aim of creating sensitive and participative methodologies appropriate to accessing, revealing and representing the social worlds of families affected by rare genetic conditions, we can see here how the stop-motion films have provided a way for participants to resist representations predominated and prefigured by a more medical model and showcase their stories and experiences from a different perspective.

Reflecting on the value of participatory animation for qualitative research

Stop-motion animation has facilitated and prompted new conversations, drawn previously hesitant voices in, built connections between story tellers and given our participants a modality of telling us about their concerns, the challenges they face, and the moments and encounters in their lives that mattered. Could we have had a conversation about these things without playing with plasticine? Certainly. But would we have understood quite as viscerally? And would we have ended up with such rich conversations, with participants feeling a sense of solidarity from watching each other's films and seeing some of their experiences reflected back at them?

"With those words at the end, we've all got examples of things that medical professionals have said, they do stick with you for years."

"Her film was obviously really powerful because in that really short film, it's started a massive conversation, that everybody can just understand, I think that's really impressive."

The method enabled us to give a level of representational agency to our participants, and explore topics and themes they themselves wanted to raise and bring attention to. It has also left us with a portfolio of rich and evocative visual artefacts and transcripts of fascinating discussions to analyse. With the focus of this journal being to 'push at the boundaries of established ways of doing qualitative research' we have focussed here on offering contributions to understandings of the animation method itself, and more detailed analysis of the new knowledges offered through analysing the discussions that the processes of making-together and viewing-together prompted will be detailed elsewhere. We remain committed to treating participant's stop-motion films as data and narrative to be analysed in their own right – not just a secondary artefact of the research.

With researchers increasingly challenged to think more creatively about how they might engage different publics and stakeholders in their work beyond the written form, the filmmaking process has also provided us with a powerful resource for research communication and education, with affordances beyond accounts that remain solely textual. The films created by our participants have already been utilised as a powerful resource within the education of medical students. Showing the films prompted students to reflect critically on the importance of evaluating their language and thinking sensitively and carefully about how clinical terminology might be better explained. Others reflected on how the animations revealed things they wouldn't normally see (the frustration that

follows a prescription being made), and gave them an appreciation of how and why patients may feel dismissed. They recognised that as clinicians, they risked being desensitised to seeing things from everyday perspective of families, and commented on the value of being affectively re-sensitized to this through watching the animations.

We know that paying attention to narratives can support healthcare professionals to understand additional dimensions of their patients, with beneficial effects on patient care and outcomes (Hurwitz et al., 2012). Particularly, narrative can play a huge role in clinical education, creating an affective link and challenging assumptions, with the emotional impact of stories giving healthcare professionals motivation to change and develop as physicians (Kumagai et al., 2009). In the same way the words involved in the film ‘Professionals, remember, your words can last a lifetime’, have stayed with the filmmaker for years, the expressive power of the film might stay with healthcare professionals as a prompt to consider terminology and language choice.

Whilst we would advocate further experimentation with stop-motion animation within qualitative research, we must recognise requesting participants to create a film is a big ask. Animation is a slow process. However, there was a sense from our participants that it was both a valuable and enjoyable approach.

Participants suggested creating their animations had produced new lines of thought and reflection for them, with the creativity involved allowing an ease of representation and participation. People reflected on animating instilling a sense of permissiveness to explore thoughts and themes, and how much they had valued the sense of community, connections and togetherness that emerged during the process. Participants reported having a deadline to deliver their films by had significantly helped them to focus in, even though we as researchers felt guilty in imposing such. Rewardingly, participants described feeling empowered by the skills they had acquired:

“I didn’t know what on earth to expect with this course, and I almost didn’t do it, because I felt, do I have enough time, is it a bit frivolous, I’ll probably produce something really rubbish, I don’t think it’s my forte, but something made me want to give it a go, and I’m so glad I did, because it’s given me confidence.”

Some had even utilised their newfound animating skills as part of their campaigning and advocacy work within regional rare disease network (particularly, as a way to raise awareness of the lived experience of rare genetic disease). It again speaks to the prospects of the method to be self-illuminatory, that having time to explore these topics has been empowering and encouraged people to advocate, share and find a new and different voice. For us, wanting to avoid an extractive research paradigm and create an approach more centred around a participatory ethos, this felt gratifying and worthwhile. As DeLyser and Sui (2014: 300) note, in participatory research, “‘success’ emerges not only from knowledge gained by/for the researchers, but also from the development of participants’ knowledge, understandings, skills, and capacities’. This reciprocity was important for our own ethos of research.

There is of course a danger to arts-based methods, that their value remains (sadly) contested (Finley, 2008), perhaps, to draw on the language of the quote above, imagined

as frivolous, both by participants, peers and other stakeholders. Certainly, these short films do not tell us everything about the social worlds of families affected by rare genetic conditions who are caught up amidst genomic excitement, however, they have provided a new method of storying those worlds (Cameron, 2012; Haraway, 2016).

Conclusion

There is a growing literature that recognises the place of storytelling as method (Cameron, 2012; Gallagher, 2011; Satchwell et al., 2020). Storytelling via stop-motion films can direct attention towards ‘the ways in which personal experience and expression interweave with the social, structural, or ideological’ (Cameron, 2012: 574). Whilst, as Cameron (2012: 588) explains, we ‘cannot know in advance where our stories will lead’, a politics of valuing the local, the situated and the specific can create opportunities to challenge larger discourses, and ‘it may be that it is precisely in small, local storytelling that political transformation becomes possible’. This, as Cameron (2012: 586) reminds us, requires ‘experiments in narration’ to get away from ‘didactic or expository prose’ and instead find new ways to provoke attention. Our efforts with stop-motion storytelling are precisely this. We know that stories have lives, travelling and resonating in unexpected and unplanned ways (Parr, 2021). We will be continuing to share our participant’s stop-motion stories, talking about them at events, using them in teaching, and we know that participants have – and will continue to – share their films too. This article – and future articles – will lead to new lines of flight for these tales, and we hope might prompt greater understanding of the lived experiences of families whose lives have become entwined with the genomics agenda.

In looking at animation-as-method, we have highlighted the value and usefulness of participatory, creative and visual methodologies for studying the social worlds of health and disability. We have focussed on stop-motion animation here as a type of participatory animation and participatory video, and it is a method we would advocate qualitative researchers explore further. Though with caution also, as central to our success has been the opportunity to draw on the expertise of an artist with established expertise in the artform.

Stop-motion proved a highly accessible way for our participants to produce their films. Central to this accessibility was all our participants having smartphones, capable of supporting the filmmaking. Without wishing to downplay the issue of digital poverty (a key challenge for this type of participatory research), approaches previously requiring specialist equipment and training can now be found in the palm of one’s hand – quite literally. Even when reading literature on participatory video methods dating back only 10 years (Milne et al., 2012), it is remarkable how much technological situations have changed. As technology and computing continues to develop, and people become increasingly au fait with different digital skillsets, computer-animation may become a similarly accessible approach for allowing participants to render their stories and narratives visible. Yet, the analogue practice of animating by hand brought additional things to the fore, embodied narratives emerging through the messiness, unreliability and slow

crumbling of clay puppets. There are clearly different experiences – and as a result, stories – at stake here.

We have confirmed through this project that we should be as equally interested in generative processes as we are in outputs, and in thinking about the former we need to think about the opportunities it creates for accompanying conversations and experiences. Both creating and watching have been individually important here, producing different, though complementary, affects, conversations, and insights. Whilst it is easy to focus on moments of making-together, moments of viewing-together are also intrinsic to the value brought about by participatory animation or video methods.

The stop-motion stories our participants produced shine a light on many facets of everyday life and clinical care as it is experienced by families affected by rare genetic conditions at a time when whole-genome-sequencing is beginning to remap hopes and expectations. They highlight, with humour and emotion, the importance of language and interpersonal relationships and evoke the personhood of the people whose genomes are at the centre of cutting-edge science like the 100,000 Genomes Project. They make visible those who are too often forgotten or rendered passive. They remind us of the labour (emotional and social as well as physical) parents undertake as carers for their children, and the persistence of seemingly simple yet everyday barriers to accessing quality care and societal understanding. It is telling that, three films start off with a smile, an image of happiness or contentment, that is then disrupted by external forces. Above all, these stories showcase the liveliness of the social worlds of rare genetic disease. If finding ‘ways to make living systems actually come alive’ (Deacon, 2000: 97) is the goal of qualitative research, then stop-motion storytelling certainly has a role to play.

Acknowledgments

We are incredibly grateful to those who participated in our stop-motion storytelling workshops and would like to acknowledge their invaluable contributions in producing such thought-provoking and emotive films, and allowing us to share some of these as part of this article.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This research is part of The Ethical Preparedness in Genomic Medicine project, which is funded by a Wellcome Trust Collaborative Award in Humanities and Social Science, Grant/Award Number: 208053/A/17/Z.

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Supplemental Material

Supplemental material for this article is available online.

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